Nursing Roles in Parental Support:

A Cross-Cultural Comparison between

Neonatal Intensive Care Units in New Zealand and Japan

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Abstract

Introduction: Past studies have indicated that nursing support reduces parental stress and anxiety during a child's NICU hospitalisation and therefore fosters the parents' abilities to cope with the difficulties they are facing. The importance of parental support has been emphasised in numerous studies in Western countries, however the nursing support which is responsive to the parents may vary between different cultures. The cultural norms of medical and nursing care environments can affect parental stress-related experiences as well as nursing roles in the NICUs across different countries. The aims of this study are, first, to compare the medical and nursing care environments of the two NICUs. Second, the study establishes any similarities and differences in sources of parental stress in the two NICUs. Third, the study illustrates the underlying philosophy of Doane and Varcoe's (2005) relational approach to family nursing and highlights the importance of relational inquiry in the process of determining the parental support which best responds to individual families' needs in the NICU.

Methods: This study analyses the nursing roles that support parents of children hospitalised in a Neonatal Intensive Care Unit (NICU). It is a cross-cultural comparison between two NICUs, one in Christchurch, New Zealand and the other in Tokyo, Japan, with both quantitative and qualitative components. Thirty-one families participated voluntarily in the study from each NICU (n=121). The three main sources of data were a NICU staff interview, parental interview, and parental questionnaire using the Parental Stress Scale: Neonatal Intensive Care Unit (PSS: NICU) (Miles, 2002). A thematic analysis was used in order to examine parental comments.

Results: The differences between the two NICUs in terms of the NICU care environment, including NICU regulations and routine nursing care, were identified by the staff interviews, highlighting the contrasting dominant ideologies of individualism and collectivism reflected in each culture. The three sources of parental stress, measured by PSS: NICU: *Sights and Sounds*; *Baby's Appearance and Behaviour*; *the Parental Role Alteration,* were examined. The sources most responsible for parental stress differed between the four groups of parents. Overall, The Tokyo parents seemed to be most concerned about the infant's condition. The Christchurch parents, however, perceived the change in parental role to be most stressful. Additionally, only the Tokyo fathers experienced stress in association with *Sights and Sounds* more often than other areas of stress. The infant's medical/nursing care requirements, oxygen therapy and/or tube feeding, were associated with a high degree of stress for each of the parents' groups except that of the Christchurch fathers. There was a positive relationship between parental NICU visiting and stress level among the Tokyo parents while this was not the case for the Christchurch parents. The infants' and parental characteristics were

found to be associated with stress level for the Tokyo mothers and Christchurch fathers only. The thematic analysis of interview data revealed three key themes of NICU parental experiences: *Uncertainty, NICU contexts* and *Communication with staff*. These themes were identical between the two NICUs.

Discussion: This study highlighted the influence of the norms of each NICU, particularly the NICU regulations and nursing care on parental stress-related experiences, and the importance of reflecting upon these norms to critique those professional beliefs which may hamper parental coping abilities. The areas of parental support needing attention were different between the two NICUs. These areas were: the establishment of oral feeding, and infants' nursing care-related decision-making for the Christchurch NICU whilst parental information/involvement in the early stage of hospitalisation, the influence of visiting regulations, and importing Western-based NICU intervention for the Tokyo NICU. In providing these areas of parental support, the importance of effective, meaningful communication between parents and staff was equally evident in the two NICU settings. In the light of the relational approach to family nursing, this study demonstrated that *how* nurses communicate with families is not universal: one way to reach across the differences is to listen to parents, and this, it is clear, is crucial to the role of nurses in NICU settings.

研究抄録

研究題目：ニュージーランドと日本の NICU　(Neonatal Intensive Care Unit) における両親のストレスの要因と医療・看護ケア及びシステムの関係：文化的比較による NICU 看護師の役割についての一考察

はじめに：先行研究において、NICU 入院中の子どもをもつ親への看護サポートとして、親が子どもを育くむ環境を提供することはその児の成長発達を最大限に促すばかりでなく、親のストレス・不安を軽減し、その慣れない環境においても育児能力を高める鍵となることが示唆されている。しかしながら、主にこれらは西洋諸国においての研究報告であり NICU を取り巻く医療・看護ケア及その医療環境の文化的相違に関し熟慮することは諸外国で報告されている NICU における親への看護サポートを有効に活用する上で重要である。本研究は二国間の NICU において、親が感じたストレス要因及びそれらと医療・看護環境との関連性を比較考察することで、NICU という特殊な医療環境の中で、成長発達の重要な過程にある児とその家族・親の自助力を最大限に導く看護サポートのあり方について検討することを目的としている。この考察においては Doane と Varcoe (2005) が提唱している、Relational approach to family nursing ― 患者、家族、看護師、及び彼らを取り巻くそれぞれの関係性の理解を柱とした家族看護の概念を用いて展開する。

方法：本研究はクライストチャーチ市(ニュージーランド)及び東京都に位置するそれぞれ一施設の NICU を対象とした。各 NICU 施設に対する医療・看護環境に関連した質問調査、NICU 入院中の児をもつ両親への面接及び Parental Stress Scale: Neonatal Intensive Care Unit (PSS: NICU, Miles, 2002) を用いたアンケート調査を行った。各施設においてそれぞれ 31 家族（n＝121）の両親から協力を得た。データは SPSS　Version 16.0 データ解析システムを使用し、量的分析を行った。また、アンケート最後の両親からの記述式コメントについては質的に分析した。調査期間は 2007 年 11 月から 2008 年 6 月の 7 ヶ月間であった。クライストチャーチおよび東京での両親への面接及びアンケート調査についてはそれぞれ、前者は The Upper South A Regional Ethics Committee、後者は院内倫理委員会から認定を受けている。

結果：各 NICU 施設への質問調査により、二施設間における相反した文化的特徴として個人主義と集団主義の影響が、NICU の施設規則や看護ルチンケアを含めた医療環境における施設間の違いを認識することで明らかとなった。二施設ともにディベロップメンタルケアの理念を取り入れていたが、NICU の物理的環境、NICU 面会規則、看護師の労働基準、母乳栄養確立に関連する看護ケアなど様々な違いがあった。PSS: NICU を用いたアンケート調査により 3 分野の親のストレス要因（NICU の物理的環境・子どもの状態・親の役割の変化）について 2 施設において更に父親・母親グループにわけ、Mann-Whitney U test 及び Chi-Square test を用い 4 グループを比較したところ、それぞれのグループで違ったストレス要因が示唆された。2 施設間での総体的な相違点として、東京の NICU では子どもの状態、クライストチャーチの NICU では親の役割の変化が

ストレス要因として示唆された。また、東京の父親群のみがストレス 3 要因中、NICU の物理的環境について最もストレスを感じていた。重回帰(線形モデル)分析により、親のストレス 3 要因それぞれにおいて高位のストレスと児が酸素療法若しくは経管栄養法が必要である状態及び児の経口栄養確立の時期との関連性について、クライストチャーチの父親群以外の 3 グループで統計学的に有意に示された。また東京の NICU においては面会時間数など面会に関連した事項と母親群では NICU の物理的環境、父親群では子どもの状態及び親の役割の変化におけるストレスと正の相関関係を認めたが、クライストチャーチではこれらの関連性は認められなかった。東京の母親群及びクライストチャーチの父親群のみでストレス要因と子ども・親自身の個人特性(年齢など)との関連性が統計学的に有意であった。また、主題的分析方法を用いた両親からの記述式コメントの考察では、クライストチャーチと東京で同様の示唆が得られた。この質的分析では両親の NICU での経験が「先行きが見えない」・「NICU 独特の空間」・「スタッフとの対話」という 3 つの主だった状況・事柄と関連していることを裏付けた。

考察: 本研究では親のストレスの要因と NICU における病院規則やルチンケアなど NICU 独特の人的・物理的環境との関連性が示唆された。文化的背景の違う二施設の比較により、それぞれの施設での医療従事者側の児へのケア・家族への関わりに関連した信条が浮き彫りにされ、それを時として見つめなおす必要があることを提示している。本研究で検討の必要性を挙げた親への看護サポートにおいての具体案は 2 施設間で異なっている。クライストチャーチの NICU では母乳栄養確立における一貫したサポート、及び子どもの日常的なケアに関して親・家族の判断を尊重するスタッフの姿勢を見直す必要性が示された。東京の NICU では入院直後の早い時期から子どもの状態についての情報提供及び親の子どもへのケアへの参入のあり方、またそれとともに面会規則に伴う親及びスタッフに与える制限の影響の見直しが必要であると考えられた。その見直しにおいて、ディベロップメンタルケアに代表される西洋諸国で発展した看護ケアを取り入れる際にその基盤となる NICU の人的・物理的環境及びそれを育んできた文化的価値観の西洋諸国との違いを認識することは有用であろう。2 施設間でのこの様に違った具体案が挙げられたが、毎日積み重ねられる親・家族とスタッフとの対話が親へのサポートの中で重要な位置づけにあることは共通していた。Doane と Varcoe の家族看護の概念（Relational approach to family nursing）によると家族をその‘家族’のエキスパートとして捉え、共に考える姿勢をもち対話することで個々が必要とする看護サポートのあり方に導かれるとしている。日常の NICU での看護業務の中で家族が何を求めているのか傾聴することは、個々の家族が必要とする対話を阻んでいるものへの気づきの第一歩でもあり、それは NICU の看護師の重要な役割といえよう。この家族看護の視点で対話を育むことは親・家族にとり、またスタッフにとっても様々な規制のある NICU の医療環境において、それぞれの家族に必要な看護サポートへの道しるべになるのではないだろうか。

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Chapter One: Introduction

1. *Background of the Study*

Parents' well-being significantly influences their child's development. Wellness of the child may in turn affect parents emotionally, physically and socially (Santrock, 2006). A Neonatal Intensive Care Unit (NICU) is a specialised area providing medical treatment and nursing care after the birth for infants born prematurely or with congenital defects. When hospitalisation in the NICU following a birth process is necessary, this may cause unexpected and enormous stress for the parents and families of the newborn infant (Mifflin, 2003; Siegel, Gardner & Merenstein, 2002). The stress experienced during a NICU hospitalisation may strongly influence the parents' well-being, interfering with their parental skills, and therefore their infant's development even after the infant has been discharged from hospital (Davis, Edwards & Mohay, 2003). Reducing parental stress and anxiety during the infants' hospitalisation in the NICU is a key nursing support for enhancing parental skills in challenging situations. Past studies, reviewed later, have indicated that nursing support reduces parental stress and anxiety during a child's NICU hospitalisation and therefore fosters the parents' abilities to cope with the difficulties they are facing (Browne, VandenBerg, Ross & Elmore, 1999; Melynyk et al., 2006; Miles, Carlson & Funk, 1996). The importance of parental support, which starts in the very early stages of their infant's life or even before the baby's birth, has been emphasised in numerous studies in Western countries, in particular, developmental care studies (Als, 2007; Als et al., 2004; Browne et al., 1999; Kleberg, Hellström-Westas, & Widström, 2007; Young, 1996).

However, although the feelings and experiences of the parents during their NICU stay can be shared between Western and Eastern cultures, the nursing support which is responsive to the parents in each cultural context may differ. The cultural norms of medical and nursing care environments, including the NICU regulations, can affect parental roles as well as nursing roles in the NICUs across different countries. Although cross-cultural studies investigating parental responses to their child's hospitalisation have been conducted (Krulik et al., 1999; Lau, Hurst, Smith & Schanler, 2007), the relationships between such parental response and the medical and nursing care environments in each cultural context have not been the focus of these investigations. Hence, there has been an information gap in the field of NICU research in relation to parental support. Since the norms of the medical and nursing care environments of the NICU might in fact present obstacles to the ability of the parents and family to manage their situations, a recognition of these possible obstacles is fundamental in delivering parental support in the NICU setting. This cultural comparison study will aid

nurses in recognising and understanding the differing cultural norms behind their roles in providing parental support that may have a significant impact on the stress and anxiety of parents in the NICU.

2. *Aims of the Study*

This study analyses the nursing roles that support parents of children hospitalised in a NICU. It is a cross-cultural comparison between two NICUs, one in Christchurch, New Zealand and the other in Tokyo, Japan, with both quantitative and qualitative components, the former involving the use of a psychometric measure, and the latter a thematic analysis. The aims of this study are, first, to compare the medical and nursing care environments of the two NICUs, including the hospital regulations, routine nursing care and nursing staff employment status/conditions, in order to explore how cultural differences influence parental stress-related experiences and nursing roles in NICU settings. Demographic characteristics of infants, parents and the infants' required medical/nursing care are also compared. Second, the study establishes any similarities and differences in sources of parental stress in the two NICUs so as to examine nursing support required to reduce the stress for the parents and family, and enhance their coping abilities. The relationship between the parental stress sources and the demographic characteristics will be examined. Third, the study illustrates the underlying philosophy of the relational approach to family nursing (Doane & Varcoe, 2005) and highlights the importance of relational inquiry in the process of determining the parental support which best responds to individual families' needs in the NICU.

3. *The underlying philosophy of this study: Relational Approach to Family Nursing*

The philosophy of the relational approach to family nursing established by Doane and Varcoe (2005) is fundamental to this study. The authors describe their approach by saying: *"we view and approach the world through a relational lens, always assuming and looking for how people, situations, contexts, environments, and processes are integrally connecting and shaping each other*" (Doane & Varcoe, 2005, p.51). The following sections 3.1 to 3.3 illustrate three premises of this framework, and the last section (3.4) also discusses the process of inquiry, the crucial component of the relational approach. Integrating the perspective of this framework into the structure of this study enriches the understanding of the findings.

3.1 A Pragmatic Perspective

The relational approach to family nursing is built upon challenging the Cartesian view of knowledge according to which existing facts are the only truth, placing subjective and

objective knowledge apart. This Cartesian view leads to a way of thinking which excludes subjective emotions when understanding the 'objective truth' through physically recognisable and ever-changing facts (Doane & Varcoe, 2005). In contrast to the Cartesian view, Doane and Varcoe (2005) emphasise the importance of recognising facts in many forms, which relate to each other to create varying 'multiple truths', as well as understanding all these relations as truths within the individuals' unique contexts and experiences. This pragmatic view of knowledge does not separate theory and practice, however it relates the knowledge and experience of people and families in a process of knowing (Doane & Varcoe, 2005). As opposed to the Cartesian view, the pragmatic perspective is less concerned about the rightness or wrongness of a theory than how useful the theory is in fostering nurses' ability to respond to people and families. This responsiveness enables nurses to "connect across differences" (such as cultures and experiences) (Doane & Varcoe, 2005, p. 327) to promote the well-being of families. This is the goal of the relational approach to family nursing (Doane & Varcoe, 2005).

3.2 Shaping Habits in Nursing Contexts

"*People are contextual beings who live in relation with others and with social, cultural, political, and historical processes and communities*" (Thayer-Bacon, 2003, as cited in Doane & Varcoe, 2005, p. 7). The authors of the relational approach to family nursing (Doane & Varcoe, 2005) appreciate the fact that the contexts of health care settings as well as the contextual circumstances of individual nurses shape the norms and habits of the nurses and nursing profession. In relational nursing practice, Doane and Varcoe (2005) believe that it is important for nurses to be aware of their own habits and habitual ways of thinking about health which mirror 'taken-for-granted truths'. When nurses learn to recognise their own habitual ways of thinking in their practice, they are able to question the problematic assumptions informing their nursing practice and therefore develop health-promoting practice which is responsive to people and families. Self-reflection is thus a vital element of the relational approach (Doane & Varcoe, 2005).

3.3 A Socioenvironmental Understanding of Health and Practice

Doane and Varcoe (2005) claim that the dominant ideology of the Cartesian view (that the body and mind are separated) in Western society has limited nurses' attention to the contextual circumstances of patients, resulting in failure to understand possible contextual constraints of the patients which may have affected their health. The pragmatic view of knowing the multiple truths in the individuals' unique contexts facilitates a socioenvironmental understanding of health. This is because the socioenvironmental

understanding draws attention not only to the medical and behavioural aspects of health, but also to the sociological and environmental dimensions of health and a health-promoting practice (Doane & Varcoe, 2005). This socioenvironmental view of knowledge about people, their environments, and relationships between them enhances understanding of the meaningful lives of the people and families (Doane & Varcoe, 2005). In the relational approach, this understanding is collaboratively developed between people/families and health professionals so as to support the people/families in promoting their own well-being. In other words, from the socioenvironmental perspective, health-promoting practice is led by the people/families, not the health professionals (Doane & Varcoe, 2005). The socioenvironmental understanding of health and practice is also integral to the relational nursing approach (Doane & Varcoe, 2005).

3.4 Family Nursing as Relational Inquiry

The three fundamental features forming the philosophy of the relational approach have been described. The central concept of the relational nursing approach is following a process of inquiry with families, rather than focusing on a health problem. This process involves four types of knowledge: empirical, contextual, ideological and ethical (Doane & Varcoe, 2005). According to Doane and Varcoe (2005), the range of knowledge open to development is diverse, from biomedical and nursing knowledge to personal knowledge. The latter involves knowing one's self as a person and nurse, other people, contexts and most importantly, knowing how each of these relate to each other. The authors have also identified eleven skill areas that can be used as a guide through the process of inquiry with families:

1. *entering into relation: getting 'in sync' with a family*
2. *being in collaborative relation: staying 'in sync'*
3. *inquiring into the family health and healing experience*
4. *following the lead of families*
5. *listening to and for*
6. *self-observation*
7. *pattern recognition*
8. *letting be and change*
9. *collaborative knowledge development*
10. *naming and supporting capacity*
11. *emancipatory action* (Doane & Varcoe, 2005, p. 266-267).

The skills listed above are crucial in recognising the way to engage with families, and to develop further knowledge and skills in each individual's context. The authors explain that critically reflecting upon the process of relational inquiry with individuals/families best

describes how nurses can develop their knowledge in order to respond to the individuals/families and their needs. It is important that nurses take a stance of inquiry – that is, being open and ready to question their own knowledge in order to structure the best way to follow through with families in each given moment (Doane & Varcoe, 2005). During this process, knowing and responding to families often requires nurses to sort through the 'multiple truths' of the families, who are invariably in complex situations. This is illustrated as follows:

> The strength in approaching family nursing as a relational inquiry is that in doing so families and nurses can harness the power of a range of knowledges (theoretical, empirical, biological, technical, physiological, ethical, spiritual, and so on) as opposed to being limited by one theoretical framework and /or method (Doane & Varcoe, 2005, p.215).

In this research study, the crucial features that underlie the findings are illuminated by following the process of relational inquiry. The intention is to offer nurses the opportunity to reflect on the process of relational inquiry in their everyday nursing practice.

3. 4. 1 Four forms of Relational Inquiry

Empirical Inquiry: In clinical settings, empirical knowledge provides people with biomedical data that explain the patients' health condition and their required medical or surgical treatment. According to Carper's definition of patterns of knowing, empirical knowledge confirms realities that can help develop the discipline of nursing (White, 1995). However, in relational practice, empirical inquiry not only pays attention to diseases or scientific data, but is guided by a wide range of empirical knowledge which can direct nurses to explore the patients' health condition from different angles, including the patients'/families' concerns (Doane & Varcoe, 2005). As White suggested by reviewing Carper's empirical pattern of knowing, the addition of interpretive understanding to empirical knowledge would enhance the process of knowing and avoid generalisation. Listening to the patients/families for particular concerns at a particular moment is the crucial process that further directs the empirical inquiry, and which may lead to collaborative knowledge development between families and nurses (Doane & Varcoe, 2005). During this process, the patients'/families' experience and situation can also be recognised as a pattern (Doane & Varcoe, 2005). Following the families' leads will help nurses see the patients'/families' patterns of managing problems in a difficult situation. This may in turn lead to an increase in the empirical knowledge of both patients/families and nurses by identifying information necessary to the situation, thereby facilitating the patients'/families' abilities to manage the difficult situation.

Contextual Inquiry: Contextual knowledge involves reflection upon the nurses' own personal and social contexts, and habitual ways of thinking about health, people and situations (Doane & Varcoe, 2005). According to Carper's description of the patterns of personal knowing, knowing about self develops skills of knowing others and further directs nurses towards understanding individuals and their experience (White, 1995). Self-observation is an important element in relational inquiry in developing contextual knowledge about the patients and their families. Likewise, a socio-environmental understanding of individuals and their experiences is vital. This involves identifying their cultural norms and the socio-political context which may have shaped their health-related knowledge, beliefs and behaviours (Doane & Varcoe, 2005). The nursing status or health care delivery in the socio-political context also influences the individuals' experience in a particular setting, and in their socio-political environment (White, 1995). Self-knowledge and contextual knowledge together may reveal particular circumstances that positively or negatively shape individuals' life experiences. Recognising the patients'/families' and nurses' lived experiences up to the given moment may aid nurses in understanding how the patients'/families' and nurses' experiences have in turn influenced the context they are in. In this process of contextual inquiry, collaborative knowledge is developed that will strengthen patients/families capacity to promote their own health.

Ideological Inquiry: Individuals' ideologies structure their contexts, beliefs, values and knowledge. The process of ideological inquiry questions "taken-for-granted ideas" (Doane & Varcoe, 2005, p. 278). Playle and Keely (1998), for example, claim that the traditional medical- dominant ideologies allow health care providers to label patients as 'non-compliant' without understanding the reasons for their health-related behaviours which contradict expectations. The authors warn that the unequal relationship between the patients and health care providers interferes with listening to the patients about their perspectives towards their treatment and therefore hinders their abilities for self-care. This demonstrates how the 'taken-for-granted ideas' of health care delivery might possibly minimise capabilities of patients/families. Doane and Varcoe (2005) suggest when nurses challenge their own ideologies they may become more sensitive to and respectful of the different ideologies of their patients/families by realising their own 'taken-for-granted ideas'. The authors state this skill as 'unconditional positive regard', originally described by Carl Rogers (Iberg, n.d.). Taking this position in the process of ideological inquiry will lead to constructive action for both patients/families and nurses that is responsive to their values in the given contexts. Doane and Varcoe state:

> In relational practice the goal of ideological inquiry with families is not to help families see things right. Rather, in congruence with the idea of letting be and change, …, the goal is 'to affirm and re-articulate a consciousness that already exists'. (Doane & Varcoe, 2005, p. 282).

Ethical Inquiry: The way in which ethical inquiry directs a nursing practice is strongly interrelated with ideological inquiry. Nurses' own ideologies dictate their moral responsibility, which can be identified as "striving to do good" (Lindh, Severinsson & Berg, 2007, p. 134). Doane and Varcoe (2005) describe the ethical action of nurses in relational practice as eliminating hindrances to empowering patients'/families' abilities in day-to-day nursing practice. The nursing action here is based on 'doing good', guided by an understanding of the context (Doane & Varcoe, 2005). Varcoe et al. (2004) found that nurses perceive their decision-making can be constrained by their own values, as well as the values of patients/families, institutional systems, and other health professionals. The authors highlight the importance of contextual understanding in facilitating nursing ethical practice. The relational nursing approach may assist nurses in making moral decisions in each unique context with different individuals. Ethical inquiry inevitably reflects empirical, contextual and ideological knowledge of individuals, including nurses' knowledge of themselves, in order to identify the ethically best approach for the patients/families (Doane & Varcoe, 2005). In the ethically best approach to family nursing, *"naming difference and explicitly seeking to connect across those differences can lead toward more ethical and health promoting practice."* (Doane & Varcoe, 2005, p.327).

Summary

The process of relational inquiry involves four types of knowledge: empirical, contextual, ideological and ethical. These four different areas of knowledge reflect the value of the pragmatic view of knowledge, self-knowledge, and the socioenvironmental perspective in health-promoting practice (Doane & Varcoe, 2005). The relational approach to family nursing challenges nurses to utilise a broad range of knowledge, such as from human sciences to biomedical sciences, rather than adhering to a specific type of knowledge, theory or health-care model (Doane & Varcoe, 2005). In relational inquiry, contextual knowledge about families as well as about nurses themselves enhances a process of knowing about the families and their needs, and this leads to nursing actions which support the families to cope with any difficulties they face (Doane & Varcoe, 2005). Integrating the philosophy of the relational approach into this cross-cultural comparison study will facilitate a meaningful understanding of parental experiences in the two NICUs without being limited by values and beliefs of a particular theory, norm or culture. The findings and knowledge generated by this study are interpreted through the broad context of the relational inquiry process so as to understand

parental experiences and needs in NICU settings located in different cultural contexts. In the next chapter, previous research on parental stress and nursing care in NICUs, and related cultural comparison studies are systematically and critically reviewed.

Chapter Two: Literature Review

The literatures discussed in the following sections were identified by database-searching using Web of Science, Pub-Med, CHINAL, and Google Scholar searches in relation to: NICU parental stress and anxiety; developmental care; NICU early interventions and family-centred care; cultural comparisons of parental hospital experiences; and translated psychological measures. By hand-searching reference lists of the articles initially obtained, the literature-search was further expanded and completed.

1. *Parental Stress and Anxiety in NICU and use of the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU)*

Numerous studies have examined the experience of parents in relation to stress and anxiety during their infants' NICU stay. One such study (Carter, Mulder, Bartram & Darlow, 2005) evaluated differences in psychosocial adjustments between parents of newborn infants admitted to a New Zealand (Christchurch) NICU and those whose children were not. Even though experiencing a great deal of stress and anxiety may understandably be predicted for NICU parents, this study found that both groups of parents exhibited low levels of depressive and anxiety symptoms. However, in the same study, the NICU parents demonstrated significantly greater anxiety levels on Hospital Anxiety and Depression Scale than the non-NICU parents (5.9 (SD=3.8) vs 4.7 (SD=3.1); p=0.01) (Carter, Mulder, Bartram & Darlow, 2005, p. F111). Also, the number of parents scoring a high level of depression and/or anxiety, possibly requiring further medical input, was markedly larger among the NICU mothers and fathers than their counterparts, regardless of their similar general demographic characteristics, antenatal history and social functioning (Carter et al., 2005). Understanding possible factors associated with parental stress and anxiety is fundamental in order to provide quality care which responds to the parents' needs, thereby reducing stress and anxiety in a NICU. Miles, Funk and Carlson (1993) in USA developed a stress-theory based instrument, Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU), which has been widely used to evaluate parental perception of stress experienced during NICU hospitalisation. This scale identifies four parental stress sources: the NICU physical environment, the change in parental roles, infants' appearance and behaviour, and behaviours of and communication with NICU staff. In recent years PSS: NICU has been further developed and named the Parental Stress Scale (also PSS: NICU) by Miles (2002). This modified version of the PSS: NICU excludes the subscale in relation to behaviours of and communication with NICU staff, leaving the three other subscales remaining, and is a primary survey instrument used in this research project, yet studies using this new scale have not been reported in the published literature.

Therefore, past studies conducted using the original instrument, as well as other measures, are examined in this literature review.

Recent studies using PSS: NICU were consistent in their findings, indicating the change in parental roles as the important aspect behind parental stress in NICU settings (Carter, Mulder & Darlow, 2007 [New Zealand]; Lau, Hurst, Smith & Schanler, 2007 [USA]; Preyde & Ardal, 2003 [Canada]; Dudek-Shriber, 2004 [USA]; Seideman, 1997 [USA]; Shaw, Ikuta & Fleisher, 2006 [USA]). Similarly, the noticeable influence of the infants' condition on parental stress was also reported (Carter et al., 2007; Dudek-Shriber, 2004; Seideman, 1997). The other sources of stress – NICU environment and the communication with staff/staff behaviour – were often found to have a less significant relationship with stress experienced by parents in the NICU (Carter et al., 2007; Dudek-Shriber, 2004; Lau et al., 2007; Preyde & Ardal, 2003). In the New Zealand study by Carter et al., younger gestational age was found to be responsible for greater parental stress in connection with infants' appearance and behaviour. Dudek-Shriber (2004) also found that infants' younger gestational age and longer length of stay in a NICU indicated a strong relationship between parental stress and infants' appearance and behaviour. Furthermore, the Canadian study of Zelkowitz, Bardin and Papageorgiou (2007) investigated the influence of medical and sociodemographical factors on parental anxiety and the impact of this anxiety on a parent-infant interaction. The study of 156 parents also revealed that NICU parents experienced stress and anxiety, and maternal (but not paternal) anxiety became higher when the babies' weight was less and the gestational age was younger. Rather than using PSS: NICU, in this study, both fathers' and mothers' behaviour when interacting with their babies was judged by their levels of anxiety. For example, the findings suggested that the less parents were anxious, the more they positively interact with their child (Zelkowitz et al., 2007).

Interaction between parents and their infants is crucial and has a significant impact on the parental care of the child and therefore directly relates to parental roles in NICU settings. Shaw, Ikuta and Fleisher (2006) explored the influence of psychological distress among 40 parents of NICU infants in USA. Using PSS: NICU they found a strong correlation ($r=0.53$; $p<0.001$) (p.209) between severe presentation of acute stress disorder and parental role alteration. The authors suggested that parents may benefit from support in helping their babies, regardless of the severity of the infant's condition.Since parental role alteration has been reported as the primary source of stress/anxiety for many parents (Carter, Mulder & Darlow, 2007; Dudek-Shriber, 2004; Seideman, 1997; Shaw et al., 2006), researchers further investigated associating factors related to altering parental roles experienced by parents in NICUs. Using PSS: NICU, Dudek-Shriber (2004) surveyed 162 USA parents and identified

predictable aspects of infants/parents that represented particular stress sources. This research found that younger parents, parents of infants who suffer from a heart disease, and mothers scored the highest stress in change in parental roles. In particular, the impacts of the age of parents, the medical condition of infants, and the gender differences between mothers and fathers on stress response have been focused on. This is to understand individual differences and needs when providing support/intervention and encouraging parents' involvement in their infant's care. The degree of on-going parental involvement is also a key factor. An American study by Lau, Hurst and Schanler (2007) found that mothers who expressed breast milk reported less stress in parental role changes compared to those who did not.

A study conducted in New Zealand (Carter, Mulder & Darlow, 2007), investigating associations between personality factors and perceived stress sources, found that parents who presented a high grade of novelty-seeing, cooperativeness and self-transcendence rated change in parental roles as most stressful. Although particular personality traits influenced the perception of stress sources, and the level of stress experienced, differences between mothers and fathers were also found. This finding is consistent with Dudek-Shriber's (2004) and Shaw, Ikuta and Fleisher's study in terms of gender differences. The authors of these studies found that the mothers experienced greater stress in general, as well as in relation to change in parental roles (Carter et al., 2007; Dudek-Shriber, 2004; Shaw, Ikuta & Fleisher, 2006). Fathers indicated greater stress in relation to parental roles if they suffered from alcohol/drug abuse, and in relation to communicating with staff if they experienced maternal transfer (Carter et al., 2007).

Although the factors of parental stress and anxiety are complex, the research measure, PSS: NICU, captures the parents' and family's circumstances relating to the sources of stress during the infant's NICU hospitalisation. All of the above research findings from PSS: NICU imply that the medical condition of an infant, and the required medical/surgical treatment, may directly increase parental stress as well as limit the parents' involvement in the care of their baby. Most of the Western research studies discussed in this literature review suggested that parental stress and anxiety are in fact exacerbated by multiple factors; however, fostering parental involvement in caring for infants can alleviate stress and anxiety of parents in NICU settings. Nurses play crucial role in supporting NICU parents (Miles, Carlson & Funk, 1996). It may both help to reduce parental stress and anxiety during an infant's hospitalisation in the NICU, and enhance the parents'/family's ability to cope with the unexpected situations they face in the unfamiliar hospital environment. The past studies examining nursing care and support provided in NICUs are now explored.

2. *Developmental Care and Family-Centred Nursing Support in NICU*

Interventions for enhancing and optimising multiple aspects of infants' development in a NICU have been studied internationally over recent years. Developmental care is a widely known approach based on neurobiological and neurobehavioural understandings of infants' development and which highlights the role of the parent in the NICU (Als, 2007; Als et al., 2004; Browne, VandenBerg, Ross & Elmore, 1999; Young, 1996). Developmental care emphasises the importance of minimising environmental noxious stimulation in a NICU, promoting infants' ability to self-regulate by positioning and nesting/swaddling, and most importantly, supporting parents to take charge of their infants' care, eg. initiating a skin-to-skin cuddle or alleviating pain/discomfort (Als, 2007; Als et al., 2004; Aucott, Donohue, Atkins & Allen, 2002). Early intervention may significantly improve infants' development as well as families' experiences in the NICU.

The Newborn Individualised Developmental Care and Assessment Program (NIDCAP) was established by developmental specialists based in North America in the light of the theory of developmental care (Browne, VandenBerg, Ross & Elmore, 1999; Lawhon & Hedlund, 2008). NIDCAP involves intense durational observations, to assess infants' autonomic behaviour such as breathing patterns, motor behaviour and state behaviour (consciousness) in order to evaluate the self-regulatory and stress behaviours of the infants through pre- to post- medical/nursing care. This observation is vital in guiding the parents' and health professionals' response to infants' cues and therefore their needs, and leads to individualised developmental care (Als, 2007; Als et al., 2004; Lawhon & Hedlund, 2008). A Randomised Clinical Trial (RCT) was conducted by Als et al. (2004) in USA in order to examine the effectiveness of NIDCAP among 30 premature infants born at 28 to 33 weeks gestation and who were medically low risk. The experimental and control groups consisting of 16 and 14 infants respectively were evaluated at two weeks and then nine months corrected age by using neurobehavioural assessment tools, electroencephalogram (EEG) spectral coherence and magnetic resonance image (MRI). The results indicated the effectiveness of NIDCAP in infants' behaviours, brain functional connectivity and brain structural development. The authors underlined the importance of infants' experience before term, finding that this experience can alter brain structure, therefore its function (Als et al., 2004). These studies imply that early intervention in NICU can positively influence the infants and their family even after discharge from the NICU. A number of research studies evaluating NIDCAP have also shown compatible positive outcomes of infants (Lawhon & Hedlund, 2008).

However, on the other hand, the effectiveness of developmental care has also been questioned for a number of reasons, such as the relatively small sample sizes used for RCT studies (Maguire et al., 2008). In a study in the Netherlands (Maguire et al., 2008), the efficacy of two basic tools in delivering developmental care, the incubator cover and the positioning nest/bedding, was assessed in relation to the physical and neuromotor development and medical condition of 179 infants at term. This study indicated that offering the basic components of developmental care had no favourable impact, in the short term, on either infants' development or medical condition (Maguire et al., 2008). Nevertheless, parental involvement, which is a crucial aspect of developmental care, was neither specified nor assessed in this research study. Possible differences in conceptual understandings of the developmental care approach/method between NICUs, especially worldwide, might cause bias when examining developmental care delivered at each institution, therefore inconsistent evaluations of the efficacy of the care may occur. Thus, in their analysis, research studies investigating the efficacy of developmental care should consider the depth of understanding regarding the theory of developmental care and its delivery, including the degree of family involvement.

Other theoretically based parent-focused interventions in the NICU have also been reported to have increased beneficial outcomes. One example is an educational-behavioural intervention for parents in the NICU, named Creating Opportunities for Parental Empowerment (COPE) and developed in USA (Melynyk et al., 2006). This programme aimed to foster parent-infant interactions and parents' knowledge in caring for their infants by providing information about infant behaviour/growth that progressed from the general down to individualised information/activities/advice. The intervention was used over four stages starting from 2-4 days after NICU admission until after the infants' discharge (Melynyk et al., 2006). The RCT study investigating 258 mothers and 154 fathers/next of kin demonstrated that although fathers did not show a significant difference, mothers in the COPE group presented less stress and anxiety than non COPE mothers. This trend was still evident when the infants were two months of corrected age. Likewise, infants of COPE parents were discharged from the NICU after a shorter length of stay than that of their counterparts (Melynyk et al., 2006). Non-stressful communication with medical/nursing staff may help parents feel less stressful in the unfamiliar NICU environment. A structural programme such as COPE provides consistent interaction between the parents and nurses to assist parents not only in increasing their knowledge but also in building up rapport with nurses. These experiences can in fact facilitate parental coping abilities and increase their confidence in dealing with uncertainty. In this way, nurses can support parents' abilities, rather than doing everything themselves. However, cultural fitness in delivering such a programme was not

mentioned in the study: therefore, further evaluations regarding the appropriateness of the Western-based educational programme for people from different cultural backgrounds should be useful.

The research findings described above also suggest that nursing support for parents during NICU hospitalisation significantly influence the capabilities of parents after their infants' discharge. The Australian study by Davis, Edwards and Mohay (2003) investigated interactions between mothers and their infants (born at less than 33 weeks gestation) at three months after the infants' discharge from the NICU as well as associated factors which were responsible for increasing/decreasing the interactions. The results indicated that increased mother-infant interactions were correlated with increased maternal coping abilities, and these were further related to perceived support from nursing staff and family. This implies that nurses have a significant role in parental support in a NICU which may eventually result in optimising infants' development in the longer term. However, these aforementioned research studies lacked overt consideration of cultural appropriateness in the support and care delivered to the infants and their families and/or consideration of cultural differences in parental response to stressful situations. For instance, the application of the philosophy of developmental care to NICUs in Eastern countries has not been closely investigated by published research studies and, therefore, the appropriateness of the use of the Western approach in Eastern countries is uncertain. Being aware of the degree and extent of their own cultural understanding, NICU staff may in turn better understand their own culture and thus themselves, and the care they deliver in their cultural context. This knowing is critical in developing cultural consideration and understanding which are fundamental aspects of parental support in NICU settings. A cross-cultural study may well provide an opportunity to reflect on our own culture and its context. Possible cultural issues that have emerged from past studies related to the NICU experiences of parents are now investigated.

3. *Parental Experiences in NICU: Cultural Comparisons and their Measures*

Parents in a NICU may perceive causes of stress/anxiety differently and respond to stress in different ways. These variations occur according to individuals' personal, contextual, social and cultural circumstances. In some past studies investigating NICU parental stress (Cater, Mulder, Bartram & Darlow, 2005; Cater, Mulder & Darlow, 2007; Shaw, Ikuta & Fleisher, 2006), the ethnic backgrounds of the participants were neither specified nor included in the analysis, while in other studies ethnic/racial differences have been reported to have influenced parental stress. For example, Dudek-Shriber's study (2004) conducted in USA found that Caucasian parents perceived the NICU physical environment as stressful more frequently than parents from minority ethnic groups. This result was congruent with an American study by

Lau, Hurst Smith and Schanler (2007). This study indicated that African-American mothers presented a lower level of anxiety as compared to their Caucasian counterparts. In contrast, another study, conducted in Canada (Zelkowitz, Bardin & Papageorgiou, 2007), illuminated a relationship between increased parental anxiety and immigrant status. These inconsistent findings are presumably a result of the relatively small proportion of minority ethnic groups included in the study. As a consequence, the effect of ethnic/racial diversity on the results of studies might often warrant attention.

Lau, Hurst and Schanler (2007) studied 163 mothers of low birth weight infants, representative of four ethnic/racial categories in order to determine ethnic/racial differences in maternal stress of and its effects on lactation. The lowest levels of maternal anxiety and desire for social acceptance were found in the African American and Caucasian categories respectively, whereas the results of other stress measures including the Beck Depression Inventory (BDI) and PPS: NICU showed no significant differences. Social desirability was also found to have a negative association with educational and financial backgrounds, anxiety and depression, and particular perceived stress sources (infants' appearance and behaviour, and communicating with staff). As the authors (Lau et al., 2007) pointed out, the desire for social approval, which varied between ethnic/racial groups, may cause bias in self-reported psychometric questionnaires. People from different cultural backgrounds may respond to the same questions in different ways, and if this is the case, the results may be ambiguous. A contextual understanding of each sample group would help in-depth analysis when comparing differences in the psychological response to stress.

Cross-cultural comparisons of stress experienced by parents in the NICU present a challenge, however, these studies might increase the cultural understanding of individual families, an understanding which is fundamental in delivering care to their infants in the NICU. Cultural differences may actually influence the norms of the medical/nursing care environment in Western and Eastern countries and can further affect parental roles as well as nursing roles in a NICU. As a result, researchers may face difficulties in understanding differences in contextual aspects that form the NICU environment and which affect parents as well as nurses. For this reason, using culturally adapted psychometric instruments is crucial. Franck, Cox, Allen and Winter (2005) investigated the American measure, PPS: NICU, with reference to UK parents by testing its consistency between 196 UK parents and 61 US parents using Spielberger's (1983) State-Trait Anxiety Inventory (STAI). This study demonstrated overall consistent results between the UK and US samples, indicating that the PPS: NICU has a good level of validity and reliability when applied to the UK parents. However, possible associated factors of stress were omitted from the analysis, such as the social backgrounds of

the families, and other related factors including experiences within 24 hours post delivery, parental visiting and infants' characteristics were tested but only for the UK samples. Thus, in spite of the overall similarities, the marginal attention to contextual differences between the two NICUs under study shows that the necessity of altering/adjusting the instrument when applying to the UK parents may have been overlooked.

Contextual and cultural considerations become even more important when using translated versions of psychometric measures in cross-cultural comparisons. Mallinckrodt and Wang (2004) stressed the importance of contextual/cultural adaptations of translated measures, emphasising the limitations of the 'item-by-item' translation approach, which may often be used in the process of so-called back-translation methods. In order to further verify back-translated versions, the authors (Mallinckrodt & Wang, 2004) developed the Dual-Language, Split-Half (DLSH) method. DLSH requires a large number (over 300) of native speakers as well as at least 30 bilingual participants to complete the process, enabling computerised statistical analyses for testing its various forms of reliability as well as validating the cultural appropriateness of the adapted measures. As the authors pointed out, the number of participants required in this process may cause difficulty, especially the recruitment of 30 bilingual individuals. Nevertheless, the use of a large number of participants may well increase the consistency between the original and adapted measures in the process of developing translated versions. When conducting cross-cultural comparison studies, an important step in determining possible biases in findings is to examine the meaning and context of each item of the adapted measure to ascertain its cultural compatibility.

Although some studies using a Japanese-modified version of PSS: NICU have been published in Japan, none of them are fully reported in English. The findings of these studies indicated the infant's condition and the change in parental roles as contributing factors of parental stress in the Japanese NICUs under study (Hori, 2000; Nakazawa, Matsuura & Nomura, 2006). However, these studies had relatively small samples (9 and 20 mothers) and the validity and reliability of the Japanese-modified version were not stated. Therefore, in order to investigate sources of stress experienced by Japanese parents in Japan, testing the reliability of the Japanese-translated PSS: NICU used in this study will be worthwhile. This could also be useful in understanding the possible cultural differences in the factors of parental stress, which may then lead to different ways of supporting parents in NICU settings.

Summary

This literature review highlights the importance of nursing roles in parental support as well as a need for further studies investigating cultural variations of nursing interventions for

parents in NICUs. The studies discussed in this chapter were consistent, stressing the value of parental involvement in the care of their infants during NICU hospitalisation. This conclusion was based on their common findings, which revealed that a change in the parental role in the care of infants is most responsible for parental stress. However, to the author's knowledge, since these studies were developed in Western countries, the applicability of the findings and their implications to non-Western countries is yet unknown. Similarly, numerous interventions for nurturing the well-being of infants and families in NICUs have been reported, however cultural considerations in providing these interventions to families from varying cultural backgrounds have barely been discussed. The lack of cultural consideration in past studies could be due in part to their limited attention to the importance of contextual understanding in providing parental support. A contextual understanding of the cultural norms of particular medical or nursing care environments may deepen awareness of their influence on parental experiences as well as on nursing roles in parental support. This contextual understanding of families is integral to the socioenvironmental view of health and nursing practice which values societal and environmental understanding of health as well as knowledge of biomedicine and behavioural disease prevention (Doane & Varcoe, 2005).

This study compares the medical and nursing care environments of a New Zealand and a Japanese NICU, and the areas of parental stress that require attention within them. The relational nursing approach (Doane and Varcoe, 2005) taken in this study, described in Chapter One: *Introduction*, leads to a crucial understanding of the parental experiences in the NICUs and of essential support which is responsive to parental needs. Based on this understanding, the relevance of applying the Western-based philosophy of parental support in NICUs to Japanese parents and families is explored. The reliability of the American psychometric measure is also assessed for its applicability to both Japanese and New Zealand parents. To illustrate the broad context of the two countries in which the NICUs under study are located, their predominant socio-political features are described briefly in the next chapter.

Chapter Three:
Background of Health Care Systems in the Two Nations

1. *The People and Lands*

New Zealand and Japan are both island nations and they display similar physical features. For example, from north to south New Zealand's land area is three quarters of that of Japan. Despite the similar geographical size, the population of the two countries is notably different. According to the New Zealand census in 2006, New Zealand has a population of a little over 4 million, consisting of diverse ethnic groups such as European (68%), Maori (15%), Pacific Islanders (7%) and Asian (9%) (Statistics New Zealand, 2008). On the other hand, the population of Japan, ranked tenth largest in the world, was 127 million in 2005, and foreign-born residents represented only 1.2 % (Ministry of Internal Affairs and Communications, [Japan], n.d.). This suggests that there is less ethnic/racial diversity in Japan than in New Zealand. Not surprisingly, the population densities of the two countries also demonstrate remarkable differences. In 2005 the population density of Japan was estimated to be 343 per square kilometre, just over seven times as high as the world's average (Ministry of Internal Affairs and Communications [Japan], n.d.), whereas in 2002 New Zealand's population density was only 14 people per square kilometre (Statistics New Zealand, 2008). This difference is less between the cities of Christchurch and Tokyo, where the NICUs under study are situated. These cities have 698 (in 2001) versus 5751 people (in 2005) per square kilometres respectively (Statistics New Zealand, 2008; Ministry of Internal Affairs and Communications, [Japan], n.d.). Christchurch is the second largest city in New Zealand, with a population of over 348,000, constituting about 8% of the total population (Statistics New Zealand, 2008) whilst over 12 million people live in the capital Tokyo, the largest city in Japan (Ministry of Internal Affairs and Communications [Japan], n.d.).

In spite of the fact that the populations of both New Zealand and Japan are slightly increasing, birth rates show opposite tendencies. In New Zealand, the birth rate was reported to have gradually increased to 14.14 per 1000 estimated mean population in 2006 (Statistics New Zealand, 2008), while the Japanese birth rate steadily declined to 8.4 per 1000 in 2005 (Ministry of Internal Affairs and Communications [Japan], n.d.). However, when comparing the maternal delivery age, the same trends in both countries are apparent. In both New Zealand and Japan, mothers' delivery age peaks between 30 and 34 years old, followed by the age group of 25 to 29. The number of mothers aged from 35 to 39 who give birth exceeds that of those who are between 20 and 24 years old. This trend is consistent with the change in the national average age of first-time mothers in both countries. New Zealand had a relatively

long history of a steady increase in the age of new mothers up to the year 2003, and this has plateaued around the age of 30.6 in recent years. Similarly, although in Japan the average age of becoming a mother is 28.9 years old, slightly younger than that of New Zealand mothers, Japan follows New Zealand's trend of a constant rise in the age of entering motherhood. In contrast, the proportion of teenage mothers is significantly different when comparing the two nations. It is estimated that approximately one in every fifteen total live births in New Zealand involve teenage mothers, whereas this figure is one in 61 among Japanese mothers (Statistics New Zealand, 2008; Ministry of Health, Labour and Welfare [Japan], n.d.).

2. *The Health Care Systems of New Zealand and Japan*

The New Zealand health care system has been uniquely developed to recognise the Treaty of Waitangi, reflecting the nature of its bicultural society. The New Zealand government controls the hierarchical health care system, including 21 District Health Boards (DHBs), which receive population-based funding and are governed by both locally and ministerially appointed members (Barnett & Barnett as cited in Dew & Davis, 1999). This health care system provides free medical care services in the public hospitals within each DHB. On the other hand, Japanese health care is based on a social insurance system, and this is comprised mainly of two types of insurance: Employees' health insurance and National health insurance (for the self-employed/unemployed). It is compulsory for all Japanese residents to contribute to this social health insurance system. This system provides subsidies to cover health care expenditures (Social Insurance Agency [Japan], n.d.). The Japanese may choose to access either public or private hospitals, however the hospital fee occurs regardless. Governmental support in relation to expenditures for delivery, which may in fact influence a family's decision to have children, is also different between New Zealand and Japan. For example, in Japan, although childbirth-related costs are not subsidised, parents are entitled to obtain a benefit (approximately NZ$4,000 per infant) (Social Insurance Agency [Japan], n.d.). Nonetheless, the parents have to pay medical costs for delivery (Social Insurance Agency [Japan], n.d.), which may well exceed the amount of the benefit. In contrast, New Zealand provides full cover by the government for such delivery-related expenditures (New Zealand Ministry of Health, 2006). In addition, although these differences in the health care systems, parental support/educational sessions such as antenatal classes are provided by the government in both countries (New Zealand Ministry of Health, 2006; Ministry of Health, Labour and Welfare [Japan], n.d.).

With regard to infants' admission to the Neonatal Intensive Care Unit (NICU), the two countries operate differently. New Zealand has six neonatal units providing intensive care

facilities, and all six units are operated by a local DHB (Auckland District Health Board, 2008; Canterbury District Health Board, 2003; Capital & Coast District Health Board, 2008; Otago District Health Board, n.d.; Waikato District Health Board, 2008). One of these is the Christchurch NICU discussed in this study, which covers not only the city but also the surrounding regions, accounting for over 13% of the national population. There were over 7500 live births in this area of coverage in 2007 (Statistics New Zealand, 2008). In comparison, Tokyo has 22 NICUs, making up a total of 195 beds, located within tertiary medical institutions (both public and private). These NICU are completely independent of one another, and people can access any hospital irrespective of where they live (Tokyo Metropolitan Government, n.d.). The 22 units are responsible for mainly the central Tokyo city, where over 100,000 live births were reported in 2002 (Tokyo Metropolitan Government, n.d.). These differences in NICU management between the two countries may well have influenced the development of the neonatal care services of New Zealand and Japan in different ways. Health care support, including medical costs, is a case in point. Japanese parents are expected to apply for a subsidy in the event of NICU admission. If the application is delayed, hospital regulations may require full/part payment for the hospital stay, including everything from medical costs right down to the cost of baby formula (if bottle-fed) at discharge (Associate Charge Nurse, personal communication, Tokyo NICU, 26 January, 2008). This is the case for the Tokyo NICU studied in this research. This is not the case, however, for New Zealand parents whose infants are hospitalised in a NICU.

Summary

In this chapter, the socio-political features of the NICU settings of the two countries have been described in brief. New Zealanders and the Japanese may have different norms and expectations in regard to their utilisation of health care services, and this has been strongly influenced by the structures of the health care system in place in each country. These structures might in turn have formed the expectations of the health care services towards their people. As health care services at the bottom of the health care management hierarchy directly provide care for individuals, understanding the cultural norms and expectations of these service providers is crucial. This understanding will aid nurses in recognising the norm of NICU settings which may limit individuals' coping abilities.

Chapter Four: Method

This research is a cross-cultural study of two Neonatal Intensive Care Units (NICUs) in Christchurch, New Zealand and Tokyo, Japan involving both quantitative and qualitative components. The three main sources of data collection were: a NICU staff interview, parental interview and parental questionnaire. The data collection periods were: 12 November 2007 – 18 March 2008 in the Tokyo NICU; 25 March 2008 – 27 June 2008 in the Christchurch NICU.

Key Research Questions

1. How do the two systems handle the care of NICU infants and their family and are there differences in:

NICU characteristics?

- Medical conditions/ criteria for admitting to NICU
- NICU physical environment
- NICU staff

Nursing staff?

- Numbers of employed nursing staff
- Employment status
- Working conditions (shifts/ working hours)
- Patient-nurse ratios

2. How do the roles of nurses differ, particularly in relation to:
    - Nursing models/approaches?
    - Routine nursing care?
    - Parental support?
3. How do the roles of family differ, particularly in relation to:
    - NICU regulations: visiting hours?
    - Family involvement in the care of their infant in the units?
    - Preparation for discharging from the NICU?
    - NICU discharge follow-up systems?
4. How do the characteristics of infants, their parents and family, and external family support differ?
5. How do the influences of medical and nursing care environments differ between the two NICUs, particularly in relation to:
    - Parental perception of the sources of stress?
    - Associated characteristics with the sources of stress?

6. Are there ways in which the levels of parental stress and anxiety during hospitalisation could be reduced by particular parental support?
7. What does the parental support required in both countries imply for the nursing role?

1. ***NICU Staff Interview*** (appendix A)

Information related to the NICU medical and nursing care environments as listed under *Key Research Questions* 1 to 3 was obtained by interviewing NICU staff with various roles in both units. Five (in the Christchurch NICU) and two (in the Tokyo NICU) individuals were interviewed separately without a formal process of written consent. The collected information is described in Chapter Five: *The Two Neonatal Intensive Care Units*.

2. ***Parents' Participants***

A total number of 121 parents, consisting of 29 pairs of parents and one additional mother and father (31 families) from the Tokyo NICU and 30 pairs of parents and one additional mother (31 families) from the Christchurch NICU, participated voluntarily in this study. The participation rates in the two units were 89% in the Tokyo NICU and 92% in the Christchurch NICU. This represents these percentages of parents who agreed to participate after being approached to be included in the study. All the participants met criteria as listed below:

The inclusion criteria:

- Biological parents whose child was born prematurely (up to 34-weeks gestational age at birth) or had a congenital disease requiring NICU hospitalisation
- Parents with marital or de facto status
- The length of stay in the units was two weeks or longer
- Parents were residents of each country
- Parents' first language was English for Christchurch participants and Japanese for Tokyo participants
- The child's condition was considered before approaching the parents for participation

The exclusion criteria:

- The child was in palliative care
- The child's condition was a result of parental drug abuse
- A major parental mental illness

3. *Parental Interview* (appendix B/C)

The interview with parents elicited the following information in response to *Key Research Question* 4:

- Infant's characteristics: gestational age at birth and postmenstrual age [1]at the time of interview, birth weight, required medical treatment such as respiratory assistance, type of feed and feeding, and current use of an incubator
- Family's characteristics: parental age, ethnicity, educational backgrounds, occupation including working hours, family members in the household, and living area
- Support: external support (yes or no), key support person, type of support, and NICU visits (by parents and others)

4. *Measure*

Parental Stress Scale: Neonatal Intensive Care Unit (PSS: NICU) (Miles, 2002)[2] (appendix F):

This is a 35–item instrument including three subscales assessing specific sources of stress: the physical environment of the NICU (*Sights and Sounds*), the infant's condition (*Baby's Behaviour and Appearance)*, and the change in parental roles (*Parental Role Alteration).* Each item is rated on a Likert-type rating scale: 1= Not at all stressful, 2= A little stressful, 3= Moderately stressful, 4= Very stressful, and 5= Extremely stressful.

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4.1 The Two Focuses of Stress Level: Scoring Methods of PSS: NICU

Miles, Funk and Carlson (1993) suggested two methods of scoring the PSS: NICU in order to examine both the Stress Occurrence Level (Metric 1) and the Overall Stress Level (Metric 2). The Stress Occurrence Level (Metric 1) reflects the degree of stress experienced by parents in a particular situation they have experienced which is described in each item. When scoring, items reported to have been not applicable (not experienced) by the parents, are rated as missing. On the other hand, the Overall Stress Level (Metric 2) indicates the degree of stress caused by the NICU environment regardless of each parent's situational experience. For scoring the Metric 2, the particular situation described in each item reported to have been not applicable (not experienced) by the parent, is rated as 1 this time, indicating the situation did not cause any stress for the parent. In this current study, Metric 2 (the Overall Stress Level) scoring method is used (See chap. 6.2, pp. 43-44).

[1] Postmenstrual age refers to "the time elapsed between the first day of the last menstrual period and birth (gestational age) plus the time elapsed after birth (chronological age)" (committee on Fetus and Newborn, 2004, p. 1362)

[2] The questionnaire is available online (see References, p. 97). The process of obtaining permission to use the PSS:NICU was completed as per the instructions given by the authors of the questionnaire.

4.2 Sources of Evidence of PSS: NICU

4.2.1 Reliability and Validity of the original measure:

Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU) (Miles, 1993)

The initial psychometric evaluation for PSS: NICU was performed by Miles, Funk and Carlson (1993). Reliability coefficients were tested using Cronbach's alpha[3] on both Metrics discussed above. The alpha coefficients for the two Metrics were above 0.70 for each subscale in the original PPS: NICU, and internal consistency for the total instrument ranged from 0.94 (Metric 1) to 0.89 (Metric 2), indicating good internal consistency. Inter-scale correlations were also calculated between the three subscales: the NICU environment, the infant's condition and the change in parental roles, and the total scores in each Metric. The results of Pearson correlations showed moderate to strong correlations between the subscales and between the subscales and the total scores. Lastly, the construct validity of the PPS: NICU for both Metrics was tested with Pearson correlation coefficients by comparing them with the scores of the state anxiety scale of Speilberger's State-Trait Anxiety Inventory (STAI) (1983). In the process of validation, each score of the PPS: NICU and STAI was computed; all the correlations were $p<.001$ indicating a high level of significant, except one scale (the NICU environment) which showed $p<.05$.

4.2.2 Reliability of the modified measure:

Parental Stress Scale: Neonatal Intensive Care Unit (PSS: NICU) (2002)

There are five new items in the parental role alteration subscale, and six new items in the infants' condition subscale. The psychometric testing was originally completed in this study as per the authors' recommendation and the results will be presented in *Chapter Five: Result*.

4.2.3 Method of Japanese translation of PPS: NICU (appendix G)

The Japanese-translated version of PSS: NICU was originally completed for this study by two English-Japanese bilingual translators using a back-translation method. The translators were not familiar with PSS: NICU and had never had contact with one another. First, the original English version was translated into Japanese, then this was translated back into English by the second translator. Finally, the back-translated version was examined for its consistency with the original version by the researcher in consultation with her supervisors and a professional English-Japanese translator. Two items required further back-translation and this was completed. In addition, wording of three more items and two explanatory sentences in the Japanese version of PSS: NICU were altered after the final back-translation

[3] Cronbach's Alpha calculates occurrences of matched answers to related questions and is often used for evaluating internal consistency (ranging from 0 to 1, with satisfactory levels of consistency at 0.8 or above) (Lang & Secic, 2006).

method. This verified Japanese-translated version of the questionnaire was then reviewed by 15 native Japanese speakers, including a parent, doctor, and nurse, so as to modify the wording in accordance with cultural appropriateness. During this final modification of the Japanese version, wording was carefully selected by discussion with each individual who committed to this Japanese translation procedure in order to maintain the original meaning of each item. Throughout the process of developing a Japanese version of PSS: NICU, translation and back-translation were characterised by a high degree of consistency. Subsequent modification focused on a few items only, to remove ambiguity or potential misunderstanding resulting from the literal idiomatic translation of terminology used in the English version. Internal consistency of this Japanese-translated version of PSS: NICU is also reported in Chapter Five*: Results*.

5. *Parental Comments: Their experiences in the NICU*

In addition to completing the PSS: NICU, the participants were also asked to feel free to share any experiences that had been stressful during their child's stay in the NICU. Blank writing space was provided on the last page of the questionnaire, PSS: NICU.

6. *Procedure*

The data collection was carried out generally in the same way between the two NICUs with some exceptions, which are discussed later. Prospective participants (parents) were recruited after consulting with the clinical supervisors for eligibility, and were initially introduced to the researcher by the clinical supervisors at each unit in Tokyo and Christchurch. The recruitment began two weeks after admission. The parents were then invited to participate in this study by being offered a parental information sheet (appendix H & I) and consent form (appendix J & K). On the return of the signed consent form, or a verbal consent, a date and time for the parental interview were made. Parents who verbally consented returned the consent form at the time of the interview or on the return of the questionnaire after the interview. The parental interview was held in a room adjacent to the NICU or within the unit. Privacy was maintained at all times. It was entirely the parents' choice as to whether both or one of the parents attended the parental interview. Similarly, other key persons including nursing staff or family members such as an infant's sibling were also present during the interview when the parents wished. The interview was completed in less than 30 minutes and at the end of the interview the questionnaire was given to the parents to fill in. The parents completed the questionnaire either during their NICU visit or at home, and then returned it to the researcher in person or via nursing staff in the Tokyo NICU or via NICU reception in Christchurch. The return date of the questionnaire was recorded. The interview

and the questionnaire were completed while the child was still hospitalised in the NICU.

Exceptions in the data collection procedure in the Tokyo NICU:

Twelve pairs (out of 31 pairs) of Japanese parents self-completed lists of demographic questions (closed questions with some open-ended questions; appendix D) instead of attending the parental interview. At the same time, the parents also completed the PSS: NICU. This alteration in data collection was made due to time constraints during the NICU visit reported by four pairs of parents who wished to participate in this study. After receiving the completed lists of the questions, the researcher discussed these with the participants in order to clarify the meaning of some answers given. During this process, some of the demographic questions were modified by the researcher after each pair of parents had completed them so as to improve their clarity. Of the other eight pairs of parents, three pairs were directly recruited by the researcher, but they completed the demographic questions (appendix E) and the PSS: NICU after the researcher had left the country. This was due to the researcher's time-limit for staying in Japan. The clinical supervisor in the Tokyo NICU recruited the other five pairs of parents so that the total number of participants had reached 60 (the recruiting rate of the Tokyo NICU stated in section 1: *Participants* excludes the number of participants who were recruited by the clinical supervisor in the Tokyo NICU). The final version of the modified demographic questions was used for the eight families. Additionally and importantly, the signed consent form was also obtained from those participants who were recruited by the clinical supervisor.

Exceptions in the data collection procedure in the Christchurch NICU:

Due to the fact that the average length of NICU stay in 2007 for infants born at 34 weeks gestation was reported to be 15 days (excluding two cases) in the Christchurch NICU (Clinical Director, 12 March, 2008; Data Manager, 11 June, personal communication, Christchurch NICU), the commencement for recruiting the participants was brought forward as necessary. After consulting with the clinical supervisor, the researcher approached the prospective participants of infants born at 34 weeks gestation (or late 33 weeks) only 10 days after admission.

There were also exceptions in regard to obtaining consent from the anticipated participants in Christchurch. Two participants (from different families) returned the completed questionnaire with no consent form attached. Both participants left the questionnaire at the NICU reception, as discussed, on the day of their infant's discharge. These participants were still included in this study as they had given verbal consent prior to completing the questionnaire and the interview.

7. *Data Entry and Analysis*

7.1 Quantitative data

SPSS Version 16.0 was used for the quantitative data analysis in this study. The quantitative data collected by the parental interview and questionnaire, the PSS: NICU, were first entered into excel spreadsheets before inputting into SPSS data formats. There were four main areas of analysis:

1) Comparisons of the demographic characteristics of the two NICUs: The *t* test[4] and Chi-Square[5] test were used for these comparisons.
2) Testing internal consistency of the questionnaire: PSS: NICU was scored according to Metric 2 (the Overall Stress Level) scoring method as discussed in Section Four: *Measure* in this chapter. Internal consistency of both the English and Japanese versions of the PSS: NICU was tested using Cronbach's Alpha test.
3) Comparisons of sources of parental stress between the four groups of parents (Christchurch mothers; Christchurch fathers; Tokyo mothers and Tokyo fathers): The sources most responsible for high levels of stress were compared using the Mann-Whitney U test[6]. The situations experienced by parents relating to high levels of stress were also examined by the Chi-Square test.
4) Comparisons of associated characteristics of the stress sources between the four parents' groups: Relationships between the degree of parental stress in each situation described in an item of the questionnaire and each demographic characteristic were first identified using the Chi-Square test and Mann-Whitney U test or *t* test. Based on these results, the demographic characteristics associated with each of the three areas of parental stress were then investigated using the multiple linear regression analysis[7].

7.2 Qualitative data

Parental comments were examined using a thematic analysis method. The Japanese-written comments from the Tokyo participants were first translated into English by the researcher.

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[4] *t* test is a parametric test, used for determining differences between the two groups. Normal distribution of the data in both groups is required (MacFarland, 1998).
[5] Chi-Square test is a non-parametric test, used for examining differences in proportions of categorical variables between two or more groups (MacFarland, 1998).
[6] Mann-Whitney U test is a non-parametric test, used for identifying the existence of a difference between the two groups. This test can be used for data which do not have normal distribution (MacFarland, 1998).
[7] Multiple linear regression is used for assessing the association between two or more continuous or categorical explanatory (independent) variables and a particular continuous outcome (dependent) variable (Lang & Secic, 2006)

8. *Ethical Considerations*

This study has been given approval by the Upper South A Regional Ethics Committee, dated 19 February 2008, in New Zealand. The permission to conduct this research study was also given by the institution based ethics committee of the Tokyo NICU. The clinical supervisors were allocated by each unit.

Chapter Five:

The Two Neonatal Intensive Care Units

In response to the key research questions 1 to 3 described in the previous chapter, this chapter presents the medical and nursing care environments of the two units under study. The lists of information that follows were collected by interviewing the NICU staff in each unit.

1. *The Neonatal Intensive Care Units and their Infants*

The Christchurch NICU has a capacity of 10 beds at the intensive care level (level III), along with 30 beds for the level II/I nursery whereas the Tokyo NICU provides 12 intensive care beds and 24 level II/I nursery beds. In the former, the criteria for admission to the unit are premature infants born at less than 36 weeks gestation and/or with a birth weight of less than 2500g, and in the latter, those who were born at less than 37 weeks and/or have a birth weight less than 2300g. The criteria also include infants who are born with a birth defect/congenital disease requiring medical attention, as well as babies who require short-term medical assistance after delivery (Associate Clinical Charge Nurse, personal communication, Tokyo NICU, 26 January, 2008; Discharge Nurse Facilitator, personal communication, Christchurch NICU, 13 May, 2008). The number of infants admitted to the unit in Christchurch was just over 720 in 2006, including about 200 infants born prematurely, ranging from 23 to less than 36 weeks gestational age (Data Manager, personal communication, Christchurch NICU, 11 June, 2008). About 180 premature infants born at between 22 and 36 week gestation were admitted to the Tokyo NICU in 2006 (the Japanese calendar year), (Neonatologist, personal communication, Tokyo NICU, 8 December, 2008).

2. *NICU Physical Environment*

Although a similar number of infants is admitted to each NICU, the size of the units is considerably different. Both NICUs have one room for the intensive care level which meets the recommended standard for each infant's care-space in each country: 14 square meters (White, 2006) in the Christchurch unit and 9 square meters in the Japanese unit. For the level II/I nursery, the Christchurch NICU has five rooms to occupy 34 infants and their families, whereas the Tokyo NICU manages 24 infants and their family in the same room. The infant care-space for the level II/I nursery room(s) is 10 square meters in the Christchurch NICU, compared to 2.9 square meters in the Tokyo NICU. The lighting is adjusted according to the time of the day in both units, ranging in the intensive care area from 10 Lux to 100 Lux in Christchurch and 30 Lux to 650 Lux in Tokyo. The use of lighting also differs between the two units in the level II/I nursery: between 10 and 300 Lux, plus daylight in Christchurch, and between 20 and 650 Lux in Tokyo. Both NICUs utilise monitors, respirators, Continuous

Positive Airway Pressures (CPAPs) and infusion pumps all of which have alarm systems, however neither unit has clear regulations for controlling the noises emitted by these alarms (Associate Charge Nurse, personal communication, Tokyo NICU, 26 January, 2008; Clinical Engineer, personal communication, Christchurch NICU, 5 June, 2008).

Figure 1. The Level III Nursery: The Christchurch NICU

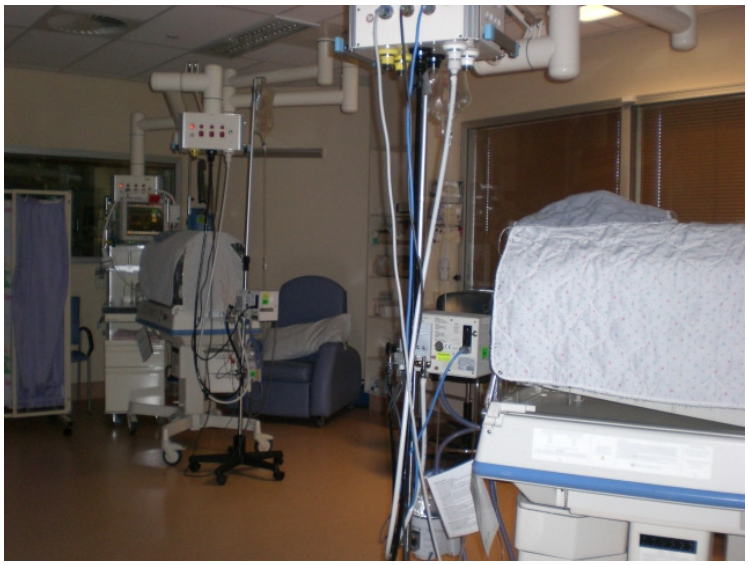


Figure 2. The Level III Nursery: The Tokyo NICU

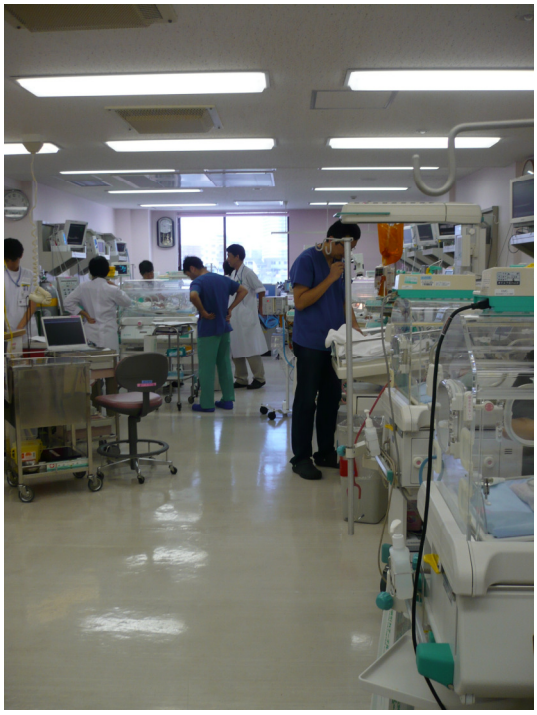


Figure 3. The Level II/I Nursery: The Tokyo NICU

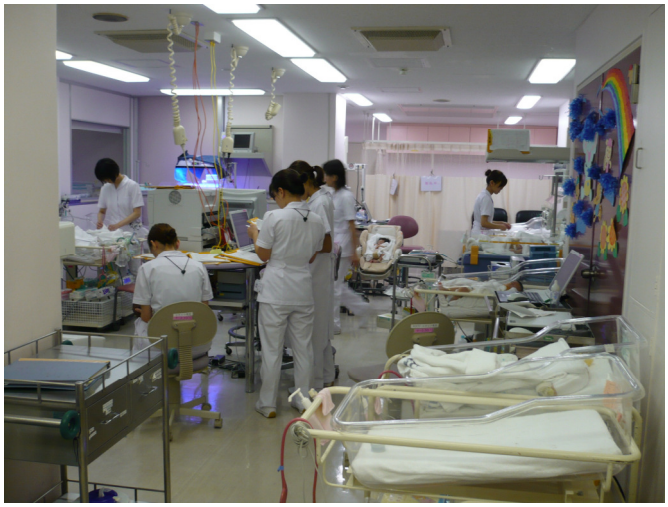
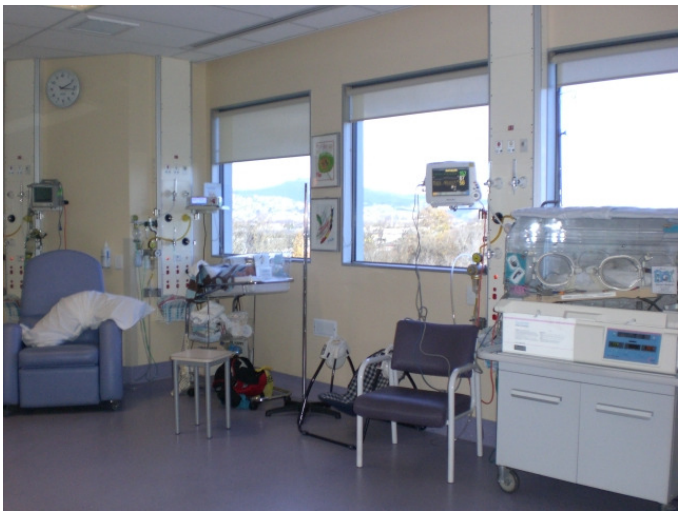


Figure 4. The Level II Nursery: The Christchurch NICU



The photos reproduced by courtesy of each NICU

3. *NICU Staff*

The multidisciplinary team (MDT) approach is the basis of support and care for the infants and their parents/family in the Christchurch NICU under study. The team includes neonatologists/doctors, nurses/midwives, discharge nurse facilitators, social workers, a physiotherapist, a dietician, speech language therapists and an occupational therapist. These team members normally work within the NICU or the child's and women's health service to which the NICU belongs. When required, a meeting is held between the MDT and family. Similarly, multidisciplinary health professionals are involved in the support and care of infants and their family in the NICU in Tokyo. However, since neonatologists/doctors and nurses/midwives are the only NICU staff, other health professionals, who cover all the wards

and units in the hospital, are appointed to see particular infants and families only when required. This MDT involvement continues after the infants' discharge and the community system gradually takes over the care for the infants and their families as needed in Christchurch (Associate Charge Nurse, personal communication, Tokyo NICU, 26 January, 2008; Discharge Nurse Facilitator, personal communication, Christchurch NICU, 13 May, 2008).

4. *Nursing Staff and their Employment Status*

The working conditions for nurses in the NICUs are one of the important factors that influence care for infants and their family. The two units operate differently in terms of nursing employment. In the Tokyo NICU, the nursing staff are employed full-time only and are required to do two shifts: 8 hours (day) and 16 hours (night). In contrast, the Christchurch NICU employs nurses either full-time or part-time and the nurses can choose to work from 12 hour or 8 hour shifts. They can also choose whether they wish to work during the day or night. The patient-nurse ratio required by each NICU is three to one in the intensive care level and seven to one in the level II/I nursery in the Tokyo NICU, whereas it is two to one and five to one respectively in the Christchurch NICU. The number of nursing staff employed reflects the available choice regarding employment status (full-time or part-time) of nurses and the required patient-nurse ratio, as mentioned. As a result, the total number of nursing staff differs noticeably between the two sites: 37 in Tokyo and 76 (equivalent to about 58 full-time) in Christchurch. Despite the dissimilarities, the nursing staff consists of mainly females in both units (Associate Charge Nurse, personal communication, Tokyo NICU, 26 January, 2008; Neonatal Nurse Manager, personal communication, Christchurch NICU, 19 June, 2008).

The structures of nursing staff are also organised differently in each unit. For example, the Christchurch NICU has a nurse manager, associate clinical nurse managers, nurse educators, and Neonatal Nurse Specialists (NNS), who work independently from the other 76 clinical nurses. Similarly, a nurse manager and an associate nurse manager have independent roles in the Tokyo NICU. However, unlike NNS in Christchurch who work along with clinical doctors, the Clinical Nurse Specialists (CNS) in Tokyo work along with other nurses. The length of each nurse's NICU clinical experience may impact on defining their role in the structures. The average NICU experience in the Tokyo NICU is about four years, ranging from less than a year (including new graduate nurses) to over 15 years (approx. 8% nurses including CNS have above 10 years experience). The range of NICU experience of the Christchurch nurses within the clinical area is from less than a year to over 20 years. However, the Christchurch nurses must have at least a year's experience post registration in an intensive

care or paediatric areas before joining the NICU staff. Over 30% of the Christchurch NICU nurses have over ten years NICU experience. These differences in the nursing experience in NICU settings between the two units are reflected in the average age of nurses: about 27 years old in Tokyo, 44 years old in Christchurch. Another difference in the operational systems of each NICU is in the role of hospital aids that influence the workload of nurses in the clinical area. For instance, the Christchurch hospital aids are responsible for milk preparation whereas this is one of the nurses' duties in the Tokyo NICU (Associate Charge Nurse, personal communication, Tokyo NICU, 26 January 2008; Neonatal Nurse Manager, personal communication, Christchurch NICU, 19 June 2008).

5. *Nursing Models/Approaches and Routine Care*

The philosophy of developmental care is integrated into the routine nursing care of both NICUs. Despite having this shared fundamental philosophy, however, differences in nursing approaches are apparent. The Tokyo NICU follows the primary nursing model, in which a particular nurse is assigned to particular patients at admission and is responsible for coordinating the patients' care throughout their hospitalisation (Fergusson, Martin & Stibbs, 1998). In the Tokyo NICU, the primary nurses and their patients are divided into one of two nursing teams, and the nurses of each team take care of patients within the team every duty. The nursing care plan is looked over by the team members and this approach makes it possible to have continuity in nursing care for each patient and their parents (Associate Charge Nurse, personal communication, Tokyo NICU, 26 January, 2008). In the Christchurch NICU, in contrast, the nursing care plan for each patient is assessed and updated by various nursing staff on each duty, rather than being the responsibility of one particular nurse. Continuity of patient care is basically maintained by allocating the same patients to nurses from shift to shift (Neonatal Nurse Manager, personal communication, Christchurch NICU, 19 June, 2008).

As stated, developmental care is central to the nursing care of both NICUs. The two units have routine nursing care in order to deliver developmental-care-based interventions such as positioning, the use of an incubator cover and skin-to-skin contact. However, the commencement of these developmental-care-based interventions differs slightly between the two units. For example, while positioning for extremely premature infants takes place two weeks after admission in the Tokyo NICU (Associate Charge Nurse, personal communication, Tokyo NICU, 26 January, 2008), all interventions generally start right from the beginning of the infants' admission in the Christchurch unit (Discharge Nurse Facilitator, personal communication, Christchurch NICU, 13 May, 2008). This slightly different approach to

developmental care may in part be influenced by the integration of *The Baby Friendly Hospital Initiative (BFHI)*. The Christchurch NICU along with other NICUs nationwide provides care for infants and their family based on the BFHI, which was introduced by the World Health Organisation (WHO) and the United Nations International Children's Emergency Fund (UNICEF). This approach encourages breastfeeding support in any maternity settings including hospitals (UNICEF, n.d.) and the BFHI is funded by the New Zealand government (Baby Friendly Aotearoa New Zealand, n.d.). Therefore, the BFHI informs the routine nursing care in the Christchurch NICU.

Although both units apply developmental care, the integration of the BFHI approach in the Christchurch NICU may account for the dissimilarities between the two NICUs in their approach to establishing oral feeding. In the Christchurch NICU, the trial of breastfeeding is started according to each baby's feeding cues, which are assessed routinely by nurses from an early stage such as during skin-to-skin contact. In order to encourage breastfeeding, tube feeding is used as the main source of topping up the intake requirement in the process of establishing breastfeeding. Bottle-feeding may be introduced by parental choice or depending on each infant's medical condition, but the decision to introduce a bottle is normally made only in the late stages of the NICU stay. In contrast, to the nursing intervention applied in the Christchurch NICU, the Tokyo unit closely follows a step by step intervention process in terms of introducing oral feeding. For example, a bottle is introduced prior to commencing breastfeeding, when the infant's weight has reached 1500g, and then the trial of breastfeeding starts at 35 weeks postmenstrual age or with weight above 1800g. Similarly, in the Tokyo NICU transferring from an incubator to a cot is also timed according to the infants' postmenstrual age and/or weight along with their body temperature control, while in the Christchurch unit the main criteria for transferring to the cot is the temperature control (Associate Charge Nurse, personal communication, Tokyo NICU, 26 January, 2008; Discharge Nurse Facilitator, personal communication, Christchurch NICU, 13 May, 2008).

6. *The Role of Parents: NICU Regulations and Support*

As discussed above, the BFHI is fundamental to NICU regulations and support in the Christchurch NICU, and this is likely to be responsible for the differences in NICU service delivery between the two NICUs. To a certain extent the differing degrees of parental involvement, as well as other family members' input in the care of infants, in each NICU is reflected in the differences in visiting hours between the two institutions. For the Christchurch parents, visiting hours are unlimited as they are not actually considered 'visitors'. Generally, the visiting hours and the maximum number of visitors allowed at any one time apply only to other people, including the baby's siblings (Women's and Children's Health Division, 2008).

Additionally, parental visits may also be supported by subsidies including a parking allowance and a travel allowance. The former applies to all NICU parents and the latter covers petrol costs for those who live 50 km away or who suffer financially. There is also an accommodation allowance for parents who live more than 100 km away (Social Worker, personal communication, Christchurch NICU, 19 June, 2008).

In the Tokyo NICU, visiting hours are fixed at particular times of the day: four hours total in the intensive care level, six to seven hours total in the level II/I nursery. In general, visitors are limited to the parents only but other people can see the baby through a specially designed window in the level II/I nursery unit according to the parental brochure of the Tokyo NICU (Maternal and Perinatal Center, n.d.).

In the Christchurch NICU, although it depends on the infant's medical condition, parents are encouraged to be involved in their infant's care at the outset, for example, such as changing nappies, turning and positioning, taking their baby's temperature and holding a feeding tube, regardless of whether or not the infant requires an incubator or respiratory assistance such as Continuous Positive Airway Pressure (CPAP). The Japanese parents, on the other hand, become increasingly involved in the care of their infants mainly after the infants have been transferred to a cot. The two NICUs provide parental support in different ways. The Christchurch NICU encourages parents to be involved in the care itself from a very early stage. However, the Tokyo NICU has a different way of supporting parents to be involved in their child's stay in the NICU. For instance, from the infant's admission, a journal is used routinely between the parents and nursing staff on duty. (Associate Charge Nurse, personal communication, Tokyo NICU, 26 January, 2008; Discharge Nurse Facilitator, personal communication, Christchurch NICU, 13 May, 2008).

At the later stage of NICU admission, the Christchurch mothers are invited to stay in a parents' unit within the NICU facility to prepare for discharging their infant from the unit (normally 48 hours prior to discharge). While living-in, the parents increasingly take responsibility for their child's care, such as feeding, and if required, tube feeding or managing respiratory assistance. For the Japanese NICU parents, visiting hours may be altered and/or extended for those whose child requires tube feeding or respiratory assistance. However, these children may often be transferred to a paediatric ward or long-term institution before going home while in the Christchurch NICU, all the children go home directly from the unit with their biological parents/relatives or foster parents (Associate Charge Nurse, personal communication, Tokyo NICU, 26 January, 2008; Discharge Nurse Facilitator, personal communication, Christchurch NICU, 13 May, 2008).

7. *Discharge Follow-Up*

The NICU in Christchurch provides scheduled nurse visits after the infants' discharge. NICU outreach nurses follow up in the community the infants who are born less than 35 weeks' gestation and/or meet other criteria, so as to support the family in transition from the NICU environment (Discharge Nurse Facilitator, Christchurch NICU, personal communication, 13 May 2008; Neonatal Service, n.d.). The DHB covers this support financially and thus infants and their families who live in the region automatically receive care by the NICU after discharge. Unlike Christchurch NICU parents, parents in Tokyo NICU do not see NICU outreach nurses, however they may be visited by community nurses who work within a different health care service (Associate Charge Nurse, personal communication, Tokyo NICU, 26 January 2008). The follow-up clinic provided by neonatologists/paediatricians is similar between the two units in terms of its time-scheduling. However, the criteria for discharge medical investigations differ. For example, the Tokyo NICU under study routinely requires head MRI for all infants whose birth weight is less than 1500g (NICU hospital protocol, 2000) whereas in the Christchurch NICU the same examination is performed depending on each individual case (Discharge Nurse Facilitator, personal communication, Christchurch NICU, 13 May, 2008).

Summary

The above comparison of the two NICUs highlights the cultural norms of each unit. Staffing structures, NICU regulations, and medical and nursing care protocols determine the roles of NICU health professionals and facilitate/limit their roles in terms of caring for the infants and their family within the NICU system. Additionally and importantly, the differences in the degree of parental involvement between the two NICUs also indicate the strong influence of the cultural norms of the two sites. Knowing these diverse cultural norms/backgrounds is important in order to understand the contexts in which the health care systems of the two NICUs at the centre of this study have developed. Recognising the contexts in which health professionals, infants and their families exist is a crucial part of this study and this is discussed in Chapter Seven: *Discussion*. It is to be noted that the examples of the Christchurch and Tokyo NICU systems illustrated in this chapter may not reflect those provided by other institutions in New Zealand and Japan. Furthermore, this chapter is based on the information collected on the stated date only; therefore, the contents may not reflect current practice at the time of publication.

Chapter Six: Results

The characteristics of the two NICUs under study were described in the previous chapter. The further key research questions, 4 to 7 are explored in this chapter. Using quantitative analysis methods, demographic characteristics in the two units are first described. Parental stress sources in each NICU, and their associations with the demographic characteristics are then investigated cross-culturally. Parental comments are also examined using qualitative analysis.

1. *Characteristics of the Participants*

1.1 Infants: General Characteristics

The *t* test was used to examine the equivalency of the samples on selected measures. The general characteristics of the infants (Table 1) showed no statistical differences between the two NICUs, except the average birth weight (t=2.14; p<0.05): 1753g in Christchurch; 1456 g in Tokyo. The average gestation at birth was identical in both units, at 31 weeks 2 days (Standard Deviation (SD) =23 days in Christchurch; 21 days in Tokyo). Neither were any statistical differences observed in the length of NICU stay and postmenstrual age of the infants at the time of the data collection. Additionally, approximately 20% of infants in each unit had required or were planned to have surgical treatment within six months.

Table 1. General Characteristics of Infants

	Christchurch (N=33)			**Tokyo** (N=34)				
	Mean	SD	(Median)	Mean	SD	(Median)	*t*	*p value*
Gestational age at birth	31w2d	3.3w		31w2d	3w		0.07	0.94
(range)	(25w0d - 39w4d)			(25w3d - 35w1d)				
Birth Weight	1753g	653g		1456g	466g		2.1	0.04*
(range)	(670-3370)			(662-2258)				
At the time of the interview:								
Postmenstrual age	35W2d	3.2w		36w6d	4.7w		-1.6	0.11
Length of stay**	29days	22days	(19days)	42days	34days	(26days)	-1.8	0.07
Sex								
Boy	64%			53%				
Girl	36%			47%				

*statistically significant (p<0.05)

**distribution is skewed

1.2 Infants' condition: Required Treatment and Care

The three areas of treatment and care required for the infants were compared using the Chi-square test and the *t* test accordingly depending on the types of variables. The Fisher's Exact test (two-tailed) was also performed following the Chi-square test where appropriate due to the relatively small number of the variables. The three areas - the use of respiratory assistance, tube feeding including other feeding methods, and incubator/infant warmer – are

listed in Table 2. The requirement of respiratory assistance was categorised into two groups: Yes/on-going and No/less than 12 hours. The former included infants who had required any form of respiratory assistance (oxygen, CPAP(Continuous Positive Airway Pressure) and intubation) for more than 12 hours at any stage of their NICU stay from birth up to the time of the data collection. The latter included infants who had never needed respiratory support or had needed it only at birth or for less than 12 hours during the hospitalisation. Those infants who required oxygen or CPAP for less than 12 hours were counted in the following category: *Type of respiratory assistance.* The differences in the percentage of the infants who required respiratory support was significant (χ^2=10.3; df=1; p<0.001) between the two units. A high percentage (88%) of the Japanese infants required respiratory support whereas only half of the Christchurch infants needed this assistance.

Table 2. Infants' Required Treatment and Care

Respiratory Assistance	**Christchurch** (N=33)				**Tokyo** (N=33)				χ^2	*p value*
Yes/on-going	52%				88%					
No/less than 12 hours	48%				12%				10.3	0.003* **
Type of respiratory assistance:	N=22				N=31					
Oxygen	18%				32%					
CPAP	59%				29%					
Intubation	23%				39%				4.8	0.09
Total length of oxygen therapy***	Mean	SD	(Median)	N	Mean	SD	(Median)	N	*t*	*p value*
	28days	29days	(11days)	17	30days	39days	(21days)	25	-0.2	0.84
Type of feeding	**Christchurch** (N=33)				**Tokyo** (N=34)				χ^2	*p value*
Breastfeeding+/-Bottle top-up	9%				38%					
Breastfeeding+/-Tube top-up	58%				0%					
Bottle +/- Tube top up	3%				21%					
Tube feeding	30%				41%				30.4	< 0.001*
Tube Feeding:										
On-going	88%				47%					
No	12%				53%				12.7	0.001* **
Total length of tube feeding***	Mean	SD	(Median)		Mean	SD	(Median)		*t*	*p value*
	28days	21days	(19days)		35days	33days	(22days)		-1	0.3
Incubator/Infant warmer	**Christchurch** (N=33)				**Tokyo** (N=34)				χ^2	*p value*
On-going	49%				38%					
No	51%				62%				0.7	0.46**

*statistically significant (p<0.05)

** Fisher's exact test

***distribution is skewed

Similarly, the number of infants requiring tube feeding at the time of the data collection indicated a significant difference between the NICUs (χ^2 =12.66; df=1; p=0.001). Coincidently, these numbers reflected a reversal of the trends relating to respiratory assistance. While Christchurch had a large percentage of infants who required on-going tube feeding, less than half of the Tokyo infants depended on tube feeding. However, the number of infants

who required tube feeding only was similar: 30% and 41% in the Christchurch NICU and the Tokyo NICU, respectively. Those who required tube feeding included infants who required gastrostomy tube feeding (three infants out of the total 67 infants). Importantly, the methods of establishing oral feeding between the two NICUs indicated a significant difference (χ^2 =30.4; df=3; p<0.001). The Christchurch NICU mainly utilised the tube feeding method as the primary source of topping up while establishing breast feeding, and, as a result, over 90% of infants in this study were requiring tube feeding. On the other hand, bottle-feeding was used for all the Tokyo infants as the primary source of oral feeding once they no longer needed tube feeding. The infants started bottle-feeding prior to breast feeding, and bottle-feeding was used for topping up while establishing breast feeding. Despite the differences in the feeding methods, expressed breast milk was primarily utilised in both units: 78% in the Christchurch NICU and 62% in the Tokyo NICU.

In spite of these differences, it was confirmed that there was no significant difference between the two units with respect to the infants' on-going requirement of an incubator/infant warmer at the time of data collection.

1.3 Parents

The equivalency of parental characteristics was also tested using the Chi-square test and the *t* test (Table 3). The average ages of both mothers and fathers between the NICUs were not statistically different: 31 years old (SD=6) for New Zealand mothers compared to 32 years old (SD=5) for Japanese mothers, and the average age of the fathers was 35 years old (SD=7) and 33 years old (SD=5) respectively. All the Japanese participants were Japanese descendants whereas the New Zealand participants reflected a degree of ethnic/racial diversity. Over 70 percent of the participants were New Zealand Europeans (71% of mothers and 77% of fathers), however the sample group also included Maori, Pacific Islanders and other Europeans. A difference in the highest educational qualification between the fathers was significant (χ^2 =15.2; df=2; p=0.001) when taking into account the type of the tertiary education they had had. Likewise, the proportion of mothers whose babies in this study were delivered by Caesarean section showed a significant difference (χ^2=6.97; df=1; P<0.05). Nearly 80% of the Japanese mothers had a Caesarean section while in New Zealand the figures fell more or less equally between the two types of delivery: Caesarean section and vaginal delivery. In addition, just over 70% of the Japanese women were first-time mothers whereas this was the case for only 55% of the New Zealand women. Of these Japanese first-time mothers, about 80% attended formal educational antenatal classes compared to 60% of their New Zealand counterparts. However, while only 30% of the Japanese fathers

accompanied their partners, 50% of the New Zealand fathers attended the antenatal classes with their partner.

Table 3. Parental Characteristics

	Christchurch			Tokyo				
Parental Age	Mean	SD	N	Mean	SD	N	*t*	*p value*
Mother	31	6	31	32	5	30	-0.6	0.55
Father	35	7	30	33	5	30	1.1	0.26

Educational Qualification	Mother (N=31)	Mother (N=29)	χ^2	*p value*
Secondary	55%	31%		
Tertiary	45%	69%	3.5	0.07**
	Father (N=29)	Father (N=29)		
Secondary	31%	31%		
Tertiary				
University degree or higher	31%	69%		
Trade/Professional	38%	0%	15.2	0.001*

Type of Delivery	**Christchurch (N=31)**	**Tokyo (N=31)**	χ^2	*p value*
Caesarean	48%	77%		
Vaginal	52%	23%	7	0.01* **

*statistically significant ($p<0.05$)

** Fisher's exact test

1.4 Family Situation and External Support

In order to understand the socio-environmental context of the NICU parents under study, their family situation was compared using the Chi-square test and *t* test (Table 4). Firstly, the employment status of both fathers and mothers was examined in each unit. At the time of the interview all of the fathers in both units were in employment. The weekly working hours were calculated based on the parental interview in which the researcher asked the participants about working hours in a typical day and typical working days in a week. The average working hours of fathers exceeded 40 hours per week in both units, however there was still a statistically significant difference between the two units (t=-2.6, p<0.05): in a typical week Japanese fathers worked the average of 8 hours longer than their New Zealand counterparts. Likewise, the mothers' experience in terms of their work choice differed between the two units. Although the majority of both New Zealand and Japanese mothers worked before their pregnancy, most Japanese mothers had quit their work during their pregnancy or after the delivery, whereas most New Zealand mothers had chosen to take maternity leave (χ^2=13.16; df=1; p<0.001).

Although there was some degree of difference, the living situation of the parents showed similar trends between the two NICUs. For instance, a high percentage of parents in both units were living together at the time of the data collection (97% in Christchurch; 84% in

Tokyo). About 45% of the Christchurch and 30% of the Tokyo parents had other child (ren) and most of these parents were living with the infant's maternal siblings. The geographic situation of each family's residential area was also surveyed. As some parents did not live together at the time of the data collection, there were some differences in the residential area of mothers and fathers in both NICUs. In general, over 70% of parents lived within Christchurch or Tokyo, and more mothers lived within the city where each NICU was situated than did their partners. The Christchurch NICU mothers from outside of the city stayed in accommodation provided by the hospital while Japanese mothers stayed with their parents who lived within the city. However, time spent travelling to the hospital from home was considerably different between the parents in the two units. For instance, New Zealand mothers spent the average of about 20 minutes (one way) to reach the hospital, while it took an average of 50 minutes for the Japanese mothers. Seventy percent of the Japanese mothers utilised public transport, while the same percentage of New Zealand mothers used a car as their primary transport. A similar tendency was observed between the fathers in the two sites.

The figures in relation to external support were almost identical between the two units. About 60% of parents reported that they had some sort of support from a key person/s. For the parents of both NICUs the physical support given was mainly for childcare and/or housework, however the relationship of the key person/s varied between the two sites. The maternal grandparents of the infants were the most typical key persons for the Japanese parents (over 80%) whereas about 60% of the New Zealand NICU parents named both maternal and paternal grandparents of their infants as their key persons. Moreover, about 30% of the Japanese parents planned for their infants to stay with their mother at the maternal grandparents' home straight after the infants' discharge from the NICU. This was not the choice for any of the New Zealand parents, who planned for their infants to go home to live with their mother and father straight away. Additionally, some New Zealand parents reported their friends and neighbours as key persons while this was not the case for any of the Japanese parents.

Table 4. Family Situation

	Christchurch			Tokyo				
Father's working hours per week	Mean	SD	N	Mean	SD	N	*t*	*p value*
	46hours	11hours	29	54hours	12hours	28	-2.6	0.01*
Mother's Employment Status		N=31			N=29		χ^2	*p value*
Prior to pregnancy:								
Housewife		16%			31%			
Employed/Self-employed/Student		84%			69%		1.9	0.23**
At the time of interview:								
Housewife		29%			76%			
Maternity leave		71%			24%		13.2	< 0.001* **
Time: Home to hospital	Mean	SD	N	Mean	SD	N	*t*	*p value*
Mother	22 mins	14mins	31	51 mins	27mins	30	-5.4	< 0.001*
Father	27 mins	32mins	30	58 mins	38mins	30	-3.4	0.001*

*statistically significant ($p<0.05$)

** Fisher's exact test

1.5 NICU Visiting

The total visiting hours in a week were compared in order to understand an important aspect of parents' experiences in each NICU using the *t* test (Table 5). The hours represented noticeable differences between the two units (Fathers: $t=4.45$; $p<0.001$, Mothers: $t=11$; $p<0.001$) as well as between fathers and mothers within each unit. The New Zealand mothers spent the most time visiting their baby, followed by their partners (43 hours and 17 hours respectively), despite the difference in the hours between them. The Japanese mothers also saw their baby more than twice as much as the fathers did, however the length of time spent visiting each week was only one quarter of that of the New Zealand mothers. These differences could have been a result of the differing NICU regulations regarding visiting hours for parents (described in Chapter Three). The parents and their family in each unit experienced the event of the arrival of their newborn baby differently. Over 90% of Christchurch infants were visited by relatives sometime during their NICU stay, whereas just over 40% of the Tokyo infants were visited by other relatives (regulations limited this to viewing the baby through a special window) once moved from the intensive care nursery ($\chi^2=16.2$; df=1; $p<0.001$). In contrast to the regulations of Christchurch NICU, the siblings of the Tokyo infants were not allowed to be in the unit. Nevertheless, 55% of the siblings of the Tokyo infants saw their younger brother or sister through the special window. In Christchurch, 75% of the siblings visited either regularly or occasionally.

Additionally, using Pearson's correlation test, the total amount of time parents spent visiting NICU was investigated for its relationship between the time spent travelling from home to hospital for both mothers and fathers, as well as the total weekly working hours for

fathers in the two NICUs. No significant correlation was observed (r<0.2) between the parental NICU visiting hours and time spent travelling from home to hospital for any of the four groups (mothers and fathers in each unit). However, although the association was only small and not a statistically significant (p= - 0.23), a slight negative correlation was indicated (r=0. 24) between the total hours spent visiting NICU and the weekly working hours among Japanese fathers.

Table 5. NICU Visit

	Christchurch			Tokyo				
	Mean	SD	N	Mean	SD	N	*t*	*p value*
Time: NICU visit per week								
Mother	43hours	16	31	10hours	5.3	29	10.7	< 0.001*
Father	17hours	15.9	30	4hours	3.4	30	4.5	< 0.001*

*statistically significant (p<0.05)

2. *Internal Consistency of the Questionnaire: PSS: NICU*

Internal consistency of the modified version of the PSS: NICU were originally tested using Cronbach's Alpha in this study. Psychometric tests have not been reported to have been done on this modified version. Both the English and Japanese completed questionnaires were scored according to the two scoring methods (Metric 1: Stress Occurrence Level; Metric 2: Overall Stress Level) as discussed in *Chapter Four: Method* in order to examine their internal consistency. As explained in the same chapter, although both Metrics were tested for their internal consistency, only the Metric 2 scoring method was used for the main data analysis, the results of which are discussed later. Cronbach's Alpha was performed on each subscale (the NICU physical environment (*Sights and sounds*); the infant's condition (*Baby's appearance and behaviour*); and *parental role alteration*) as well as the total score, and the total score including the last question regarding general NICU experience. The test results for each NICU are shown accordingly as follows.

2.1 *Parental Stress Scale: Neonatal Intensive Care Unit (Miles, 2002)*

As Table 6 shows, the internal consistency of the PSS: NICU for the Christchurch participants indicated a good level, ranging from 0.79 to 0.95 when using the Metric 2 scoring method, except for one subscale (*Sights and Sounds*) for mothers, which was calculated as 0.56.

Table 6. Metric 2: Christchurch Participants

	Mothers (N=31)	Fathers (N=30)
Sights and Sounds (6 items)	0.56	0.79
Baby's Appearance and Behaviour (17 items)	0.91	0.91
Parental Role Alteration (11 items)	0.83	0.84
Total Score (34 items)	0.93	0.93
plus General NICU experience (35 items)	0.94	0.95

Metric 1 was also tested for its internal consistency. Despite having similar results to Metric 2 (mothers: ranging from 0.55 to 0.96; fathers: from 0.86 to 0.93), Cronbach's Alpha was not able to be performed on the fathers' total score and one subscale (*Baby's Appearance and Behaviour*), and the mothers' total score. This was due in part to the fact that according to the scoring method of Metric 1, any item with a rating of 0 was counted as missing, indicating the parents did not experience the situation described in the item. Consequently, the scores of six items were deducted from the mothers' total scores due to no variance when performing Cronbach's Alpha. In other words, due to the missing data the six items resulted in having identical scores and therefore Cronbach's Alpha was not able to be completed. The reason for the inability to test the subscale and the total score of the fathers was simply due to an insufficient number of rated scores.

2.2 *Japanese version of the PSS: NICU*

The original Japanese version of the PSS: NICU was also tested for its internal consistency. All the subscales and the total scores using Metric 2 indicated a good level of internal consistency according to Cronbach's Alpha, ranging from 0.77 to 0.94 for Metric 2 (Table 7).

Table 7. Metric 2: Tokyo Participants

	Mothers (N=30)	Fathers (N=30)
Sights and Sounds (6 items)	0.81	0.77
Baby's Appearance and Behaviour (17 items)	0.90	0.91
Parental Role Alteration (11 items)	0.87	0.85
Total Score (34 items)	0.92	0.94
plus General NICU experience (35 items)	0.93	0.94

As for the Christchurch participants, Cronbach's Alpha was not able to be fully completed on Metric 1 for the Tokyo participants. The reason for this inability to test was also insufficient numbers of rated scores. Cronbach's Alpha was not able to be performed on the total scores and one subscale (*Parental Role Alteration*) of mothers, and the total scores of fathers.

3. *The Sources of Parental Stress in NICU*

In this study, the Metric 2 scoring method was used in order to understand parental stress sources in the environments of the two NICUs in general. According to this Metric, the NICU

environments are focused on more than individuals' stress occurrence levels (Miles, 1993). The three areas of parental stress: the NICU physical environment (*Sights and Sounds*); the infant's condition (*Baby's Appearance and Behaviour*); the *Parental Role Alteration*, were examined and compared between the two units.

3.1 Higher levels of Stress experienced by Parents: The Three Stress Sources

The particular areas of NICU experiences most likely to be associated with parental stress were examined in each unit. The average number of the items which were rated as a moderate or high level of stress among all the participants were calculated according to each subscale. The differences of the average number of higher-stress items in each of the three subscales between the two NICUs were then compared using the Mann-Whitney U test. In addition, with the purpose of comparing these findings with past studies, mean scores of each subscale were also calculated. The number of higher-stress items in the three subscales was comparable with the mean scores among all groups of parents (Table 8 B and Table 9 B).

3.1.1 Mothers

Overall, the sources most likely to be related to parental stress differed between the mothers in the two NICUs (Table 8 A). The mothers in Christchurch most frequently experienced stress in relation to the change in parental role (an average of 5.3 items out of eleven: 48% of the total subscale items) followed by the infant's condition (6.7 items out of 17: 39% of the subscale). Whereas two main areas of parental stress were found in the Christchurch NICU, in the Tokyo NICU, one source of parental stress stood out: the infant's condition was found to most frequently cause stress among the Tokyo mothers (9.4 items out of 17: 55% of the total items in the *Baby's Appearance and Behaviour* subscale). This compares with 4.9 items (45%) in the *Parental Role Alteration* subscale, a percentage almost identical to that of the Christchurch NICU mothers. The Mann-Whitney U test confirmed as significant ($U=268.5$; $p<0.05$) the difference in the frequency of higher stress levels between the two units regarding *Baby's Appearance and Behaviour*. The subscale of *Sights and Sounds* least frequently produced stress in both units (1.8 items and 2.3 items out of six: 30% and 38% of the total subscale for both Christchurch and Tokyo mothers respectively). In general, Tokyo mothers reported stress-related experiences more frequently than their Christchurch counterparts (average of 16.3 items and 14.1 items out of 34 total subscale items respectively).

Table 8 A. Parental Stress Sources: The Average Number of Higher-Stress Items in Each Subscale, *Mothers*

	Christchurch		Tokyo		*p Value* **
Three Subscales	Average Number of items (% per subscale)	N	Average Number of items (% per subscale)	N	
Sights and Sounds (6 items)	1.8 (30%)	30	2.3 (38%)	30	0.17
Baby's Appearance and Behaviour (17 items)	6.7 (39%)	31	9.4 (55%)	30	0.035*
Parental Role Alteration (11 items)	5.3 (48%)	31	4.9 (45%)	29	0.69
Total Score (34 items)	14.1 (41%)	30	16.3 (50%)	29	0.25

** Mann-Whitney test

*statistically significant (p <0.05)

Table 8 B. Parental Stress Sources: The Mean Score of Each Subscale, *Mothers*

	Christchurch (N=31)		Tokyo (N=30)	
Three Subscales	Mean	SD	Mean	SD
Sights and Sounds	2.01	0.61	2.34	0.79
Baby's Appearance and Behaviour	2.32	0.85	2.75	0.9
Parental Role Alteration	2.59	0.78	2.57	0.94

Table 9 A. Parental Stress Sources: The Average Number of Higher-Stress Items in Each Subscale, *Fathers*

	Christchurch (N=30)	Tokyo (N=30)	*p Value* **
Three Subscales	Average Number of items (% per subscale)	Average Number of items (% per subscale)	
Sights and Sounds (6 items)	1.8 (30%)	2.2 (37%)	0.219
Baby's Appearance and Behaviour (17 items)	6 (35%)	5.6 (33%)	0.744
Parental Role Alteration (11 items)	3.8 (35%)	2.3 (21%)	0.02*
Total Score (34 items)	11.7 (35%)	10 (29%)	0.399

** Mann-Whitney test

*statistically significant (p <0.05)

Table 9 B. Parental Stress Sources: The Mean Score of Each Subscale, *Fathers*

	Christchurch (N=30)		Tokyo (N=30)	
Three Subscales	Mean	SD	Mean	SD
Sights and Sounds	1.99	0.4	2.22	0.78
Baby's Appearance and Behaviour	2.13	0.74	2.04	0.84
Parental Role Alteration	2.09	0.68	1.7	0.62

3.1.2 Fathers

Overall, a difference in the areas of stress which produced moderate or high stress levels for the fathers was apparent between the two NICUs (Table 9 A). As for the mothers, the fathers in Christchurch most frequently experienced stress in the relation to the change in parental role (an average of 3.8 items out of eleven: 35% of the total subscale items) as well as the infant's condition (6 items out of 17: 35% of the total subscale items). NICU physical environment (*Sights and Sounds*) were least frequently rated as moderately or highly stressful, an average of 1.8 items out of six (30%) in the subscale. On the other hand, the Tokyo fathers experienced stress in association with the NICU physical environment (*Sights and Sounds*) (an average of 2.2 items out of 6: 37% of the total items) more often than other areas: *Parental Role Alteration* (2.3 items (21%) in the subscale) and *Baby's Appearance and Behaviour* (5.6 items (33%) in the subscale). These differences between the two units were tested using the Mann-Whitney U test. This test showed that the difference in the frequency

was significant (U=295.0; $p<0.05$) between the two units regarding the *Parental Role Alteration* subscale.

3.2 NICU Experiences Shared by the Majority of Parents

In the previous section, the areas most responsible for parental stress sources were found to be different between the two NICUs when comparing the three subscales: *Sights and Sounds*; *Baby's Appearance and Behaviour*; and *Parental Role Alteration*. In order to understand the stress-related situational experiences of the parents, those situations described in the three subscale items which associated with moderate or high stress levels for approximately more than half of the mothers/fathers in each unit were compared between the two NICUs using the Chi-square test. The parental situational experiences relating to the three stress sources are represented in Table 10 and Table 11. Each item of the three stress-source subscales are listed when more than approximately 50% of parents of either unit (in **Bold)** experienced moderate or high stress levels. The items are underlined if the parents of *both* units experienced the situations causing higher stress levels for more than half of parents.

Table 10. Moderate or greater stress level experienced by approx. 50% or more of the total number of *Mothers* of one or both NICUs

	Christchurch (Total Number=31)	Tokyo (Total Number=30)	p value ($\chi 2$) when significant ($p<0.05$)
Sights and Sounds			
sudden alarm	**60%** (N=30)	**90%**	
requring respirator	32%	**53%**	
Baby's Appearance and Behaviour			
equipment nearby	**68%**	**73%**	
seems in pain	**71%**	**79%** (N=29)	
abnormal breathing	**52%**	**73%**	
bruise	**55%**	**59%** (N=29)	
weak appearance	**48%**	**73%**	
seems sad	**48%**	**67%**	
seeing needle put in	**61%**	40%	
jerky movement	37% (N=30)	**57%**	
unable to cry	16%	**55%**	0.003
small size	39%	**77%**	0.004
wrinkle	19%	**53%**	0.008
unusual color	36%	**67%**	0.02
feeding by IVF	32%	**60%**	0.04
Parental Role Alteration			
separation from baby	**94%**	**80%**	
unable to feed baby	**71%**	**70%**	
unable to protect baby	**65%**	**68%** (N=28)	
unable to hold baby	**61%**	**69%** (N=29)	
unable to have time alone	**55%**	41% (N=29)	
unable to share with others	42%	**52%** (N=29)	
unsure how to help baby	**52%**	45% (N=29)	
unable to care for baby	42%	**48%** (N=29)	
General	**86%** (N=22)	**68%** (N=28)	

3.2.1 Mothers

Situations which related to moderate or high levels of stress for approximately more than half of the mothers in each unit are listed in Table 10. Although in general moderate or high levels of stress were experienced by a greater percentage of Tokyo mothers than Christchurch mothers, at least half of the mothers in both units felt stressed by particular situations in common. For example, 90% of the Tokyo mothers as well as 60% of the Christchurch mothers experienced a higher level of stress caused by a sudden monitor alarm (*Sights and Sounds*). Similarly, about 70% of mothers in both units felt stressed by the presence of medical equipment nearby, and slightly greater number of mothers in each unit experienced stress when their baby seemed to be in pain (*Baby's Appearance and Behaviour*). In the subscale of *Parental Role Alteration,* over 70% of both Christchurch and Tokyo mothers experienced stress due to being unable to feed their baby, and most mothers perceived separation from their baby stressful (94% of the Christchurch mothers; 80% of the Tokyo mothers). Although the last item: *General,* regarding parental NICU experiences in general was answered by only 71% of the total number of the Christchurch participants, more than two-thirds of mothers in both units reported their NICU experience had been moderately or highly stressful.

Despite the common stressful situations between mothers in the two NICUs, there were five items relating to the infant's condition (*Baby's Appearance and Behaviour*) which showed statistically significant differences between the two units. For each of these five items, a greater number of Tokyo mothers experienced higher stress levels than Christchurch mothers. The greatest differences occurred for three items most likely related to the prematurity of the infant: such as their baby being unable to cry (χ^2=10.0; df=1; p<0.005), and small size (χ^2=9.0; df=1; p<0.005), and wrinkled appearance (χ^2=7.6; df=1; p<0.01).

In summary, the majority of the Tokyo mothers rated a moderate or high stress level on 20 items out of 34 items across the three subscales, while the Christchurch mothers rated higher stress levels on only 14 items out of the total of 34 items. Of these items, the Tokyo mothers seemed to be concerned about their infant's condition (12 items out of 17: 70% in *Baby's Appearance and Behaviour,* compared with six items out of eleven: 55% in *Parental Role Alteration* and two items out of six (33%) in *Sights and Sounds*). Approximately 50% of Christchurch mothers, however, perceived the change in parental roles more stressful than other areas (six items out of eleven: 55% of the total subscale, compared with seven items out of 17: 40% in the *Baby's Appearance and Behaviour*; one item out of six in *Sights and Sounds*).

3.2.2 Fathers

In general, the perception of the NICU experience was different between the majority of Christchurch and Tokyo fathers whereas there were some similarities in perception among the mothers of both units (Table 11). Approximately half of the Christchurch fathers reported moderate or high levels of stress for ten items out of the total 34 items, while their Japanese counterparts rated only four of the 34 items as moderately or highly stressful. Although only two items in each subscale were reported to be stressful, the situations relating to the NICU environment (*Sights and Sounds*) and the infant's condition (*Baby's appearance and Behaviour*) were most likely to associated with stress for most Tokyo fathers. On the other hand, most Christchurch fathers were concerned about their infant's condition (five items out of 17: 30% in *Baby's Appearance and Behaviour*). However, as for their partners, the change of parental role (four items out of eleven: 36% in the total subscale) was most responsible for producing stress for about half of the Christchurch fathers, whereas this area did not relate to high stress levels for most Tokyo fathers (0 items).

The differences in the fathers' experience were statistically significant regarding two items each in both *Baby's Appearance and Behaviour* subscale and *Parental Role Alteration* subscale. In the former, over half of the Christchurch fathers rated seeing a bruise on their baby and witnessing needle insertion as sources of higher stress, whereas less than 20% of the Tokyo fathers reported these scenarios as stressful (χ^2=14.0; df=1; p=0.001, and χ^2=5.9; df=1; p<0.05, respectively). Two items in the latter subscale produced a similar pattern: the majority of the Christchurch fathers perceived circumstances such as being unable to protect their baby (63%) and separation from their baby (73%) as stressful compared to only 27% and 43% of their Tokyo counterparts respectively (χ^2=8.2; df=1; p<0.01, and χ^2=5.6; df=1; p<0.05, respectively). Nonetheless, most fathers of both NICUs experienced stress caused by sudden monitor alarms (57% of the Christchurch fathers; 73% of the Tokyo fathers), a result similar to that of their partners. In addition, the final item regarding parental NICU experiences in general was answered by all of Tokyo participants but only 57% of the total number of Christchurch participants. More than 50% of the fathers in both units who answered this question reported their overall NICU experience had been moderately or highly stressful.

Table 11. Moderate or greater stress level experienced by approx. 50% or more of the total number of *Fathers* of one or <u>both</u> NICUs

	Christchurch (Total Number=30)	Tokyo (Total Number=30)	*p* value ($\chi 2$) when significant (p <0.05)
Sights and Sounds			
<u>sudden alarm</u>	**<u>57%</u>**	**<u>73%</u>**	
requiring respirator	37%	**63%**	
Baby's Appearance and Behaviour			
bruise	**60%**	13%	0.001
seeing needle inserted	**50%**	20%	0.03
appears sad	**47%**	43%	
appears in pain	**63%**	43%	
abnormal breathing	43%	**47%**	
unusual colour	**50%**	43%	
equipment nearby	40%	**57%**	
Parental Role Alteration			
unable to protect baby	**63%**	27%	0.009
separation from baby	**73%**	43%	0.04
unsure how to help baby	**63%**	37%	
unable to hold baby	**47%**	40%	
<u>General</u>	**<u>65%</u>** (N=17)	**<u>57%</u>**	

4. *Associated Characteristics of each area of Parental Stress*

The sources of stress most likely to be experienced by the majority of NICU parents were compared between the two NICUs in the previous section of this chapter. This section presents associations between the parental stress sources and demographic characteristics (variables) of each unit. As for the previous section, the scores of the questionnaire, PSS: NICU used for analysing these associations were based on the Metric 2 scoring method. In order to identify the demographic characteristics which were significantly associated with the degree of stress levels (high or low) in each of subscale items, the associations were first determined using the Chi-square test and the Mann-Whitney U test or *t* test. The three tests were applied accordingly depending on the types of variables. Normality of distribution was examined using the Kolmogorov-Smirnov test in order to determine whether the Mann-Whitney U test or the *t* test was most appropriate for the continuous variables. Detailed descriptions of the demographic variables were given in the first section of this chapter. The total of 24 demographic variables were divided into seven categories: characteristics of the infants and parents, required medical treatment, nursing-related care, external support for the families, family settings, and NICU visiting, as shown in Table 12. Twenty-two variables for the Christchurch samples and 24 variables for the Tokyo samples were tested for associations, with stress levels rated by the parents: either a low level ('not at all' (including situations 'not experienced') or 'a little' stressful), or a moderate or high level ('moderately', 'very' or

'extremely' stressful). Variables which had statistically significant ($P<0.05$) associations with the degree of stress levels in the particular situations described in each of the 35 subscale items were identified. There were 29 significant associations for the Christchurch mothers, and 47 for the Tokyo mothers; the numbers for the fathers were 40 and 29 in the Christchurch and Tokyo samples respectively. In addition, two demographic variables for the Tokyo parents: *Requiring oxygen (yes/no)* and *Type of oral feeding method* were not assessed as the assumptions of the Chi-square test were violated due to their unbalanced distributions. Since these demographic variables partly overlapped the other variables: *Type of oxygen therapy* and *Commencement of commencement of oral feeding (yes/no)*, they were also omitted from the variable list of the Christchurch parents. Based on these findings, the multiple linear regression analysis was performed, and its findings are illustrated in the following sections.

Table 12. Demographic Variables

Characteristics of		
	Infants	Gestational age at birth; Birth weight; Postmenstrual age; Length of NICU stay
	Parents	Age; Highest educational qualifications; Employment status; Type of delivery
Infant's requirement of		
	Medical treatment	Requiring oxygen (yes/no); Length of oxygen therapy; Type of oxygen therapy
	Nursing-related care	Commencement of oral feeding (yes/no); Type of oral feeding method; Type of feed; Cot or incubator/infant wamer' Total period of time of tube feeding
Family		
	Support	External support (yes/no); Parental plans for post discharge (Tokyo participants only); utilisation of antenatal classes
	Setting	Travelling time from home to hospital;Other child(ren) (yes/no); Father's total weekly working hours
NICU Visiting		
		Total visiting hours per week; Visited by others (yes/no;excluding baby's sibling/s)(Tokyo participants only)

4.1 Process of the Multiple Linear Regression Analysis

Linear regression analysis was used with the purpose of determining which characteristics (*Demographic Variables* in Table 12) were most likely responsible for stress levels in each of the three areas of parental stress. For this purpose, the pairs of significant associations of each parents' group identified in the previous section, were categorised into the three subscales: *Sights and Sounds, Baby's Appearance and Behaviour* and *Parental Role Alteration*.

Prior to proceeding with the linear regression analysis, missing data were replaced accordingly depending on the type of demographic variable: continuous or categorical. Using the simple imputation method (Lang & Secic, 2006), the mean scores of each continuous variable which contained a missing datum were used to replace the missing data. For Tokyo fathers, these variables were: the weekly total hours visited in the NICU and total period of tube feeding (one missing value each), weekly total working hours (two missing values), and

their infant's length of oxygen therapy (five missing values). For Tokyo mothers, there were three missing variables: the weekly total hours visited in the NICU and total period of tube feeding (one missing value each), and their infant's length of oxygen therapy (five missing values). The missing variable for Christchurch fathers was the weekly total working hours (one missing value). Additionally, the five missing values in the infant's length of oxygen therapy for the Tokyo parents were replaced by the two different mean scores depending on the type of oxygen the infants required (intubation/CPAP or oxygen/non-oxygen groups) after controlling extreme values in each group. Similarly, using the model missingness method (Lang & Secic, 2006), the missing data in the questionnaire (response variables) were also replaced by creating a rating category of 0 (zero). This method was required for the Christchurch and Tokyo mothers only (0.6% and 1.4% of all data respectively). Missing data within the categorical variables were found among Tokyo mothers only. These two single missing data were replaced into the category which represented the larger number of observations.

With the view to identifying muilticollinearity between the explanatory variables, the collinearity statistics and correlation matrix were first examined, and then the explanatory variables were eliminated accordingly. After this process, the multiple linear regression was performed using the backward elimination method as well as the stepwise selection method in order to assess consistency of the results. In the process of these methods, the effects of outlying data of the demographic characteristics were examined.

4.2 Findings

The following findings indicate that the demographic characteristics most significantly associated with stress levels in each of the three subscales: *Sights and Sounds*; *Baby's Appearance and Behaviour*; and *Parental Role Alteration* (in **Bold**), differed between the four groups of parents. Each table (Table 13 to Table 16) briefly illustrates the process of the linear regression in two parts: 1) the explanatory variables initially examined, and 2) the final regression model in the backward elimination method. The results of the stepwise method are also given below when inconsistent results were obtained from the two methods: the backward elimination and stepwise selection methods. This is required for the Japanese samples only.

4.2.1 Mothers

Christchurch Mothers

For the Christchurch mothers, infants' feeding-related characteristics were found most likely to be responsible for the stress level in the two areas: *Sights and Sounds* and *Baby's Appearance and Behaviour*. Maternal stress in relation to *Sights and Sounds* was associated with the feeding status of the infants, that is to say whether or not they had started oral feeding: the stress level was higher when babies relied on tube feeding only (slope=3.4; t=2.4; p<0.05). Similarly, the total period of time infants required tube feeding corresponded to the degree of stress in the area of *Baby's Appearance and Behaviour*: the longer the tube feeding, the greater the stress level (slope=0.3; t=2.7; p=0.01). No associations were found with any of the demographic characteristics in the area of *Parental Role Alteration* among the Christchurch mothers. The findings represent Adjusted R square of 0.14 (the commencement of feeding (Y/N) in *Sights and Sounds*) and 0.18 (the length of tube feeding in *Baby's Appearance and Behaviour*), indicating that in the variance of the dependent variables the models explained only 14% and 18%, respectively, and therefore the predictive power of the models was not strong.

Table 13. Associated Characteristics: Christchurch Mothers (N=31)

Sights and Sounds

1. Demographic Variables Entered	2. Demographic variables in the Final model	Slope Coefficients	Standard Error	*t* value	*p* value	Adjusted R square
Birth weight	**Commencement of oral feeding**	3.4	1.4	2.4	0.023*	0.14
Gestation at birth					*statistically significant (p<0.05)	
Length of NICU stay						
Type of oxygen therapy						
Commencement of oral feeding (Y/N)						
Length of tube feeding						

Baby's Appearance and Behaviour

1. Demographic Variables Entered	2. Demographic variables in the Final model	Slope Coefficients	Standard Error	*t* value	*p* value	Adjusted R square
Birth weight	**Length of tube feeding**	0.3	0.1	2.7	0.01*	0.18
Gestation at birth					*statistically significant (p<0.05)	
Length of NICU stay						
Type of delivery						
Type of oxygen therapy						
Commencement of oral feeding (Y/N)						
Cot or incubator/infantwarmer?						
Length of tube feeding						
Travelling time from home to hospital						

Parental Role Alteration

1. Demographic Variables Entered	2. Demographic variables in the Final model	Slope Coefficients	Standard Error	*t* value	*p* value	Adjusted R square
Maternal age	Length of oxygen therapy	0.1	0.06	1.9	0.07	0.08
Mother's employment status						
Length of oxygen therapy						
Travelling time from home to hospital						

Tokyo Mothers

On the other hand, associations with all three areas of stress were found among the Tokyo mothers. Their stress level related to *Sights and Sounds* was negatively correlated with the total hours they visited the unit (slope=-0.4; t=-3; p=0.005) and positively correlated with the length of oxygen therapy their infants required (slope=0.05; t=2.6; p<0.05). The stress level among Tokyo mothers in the subscale *Baby's Appearance and Behaviour* was associated with the infants' gestation at birth (slope=-0.4; t=-3.2; p<0.005) and the mothers' highest educational qualification (slope=10.7; t=2.1; p=0.05). Maternal stress was higher when infants were born at a younger gestation and/or mothers had a secondary education as their highest qualification. In relation to *Parental Role Alteration*, a positive correlation was evident with the length of oxygen therapy (slope=0.1; t=2.3; p<0.05), along with the infants' feeding status - whether or not they were fed orally (slope=8.2; t=2.7; p<0.05). When oxygen was required for a longer period and/or the infants relied on tube feeding only, the maternal stress in this area became greater. The findings indicate that the models provided a reasonable predictive power – Adjusted R square of above 0.3 on all the three subscales, ranging from 30% to 40% of the variance in the dependent variables. An inconsistent result was found for the Tokyo mothers in *Baby's Appearance and Behaviour* between the backward elimination and stepwise selection methods. The relationship between type of oxygen therapy only and the stress level was statistically significant (slope=14.8; t=2.9; p<0.05; adjusted R square=0.23) according to the stepwise method. This correlation indicated that mothers whose child (ren) required respiratory assistance (intubation and/or CPAP) had a higher stress level.

Table 14. Associated Characteristics: Tokyo Mothers (N=30)

Sights and Sounds

1. Demographic Variables Entered	2. Demographic variables in the Final model	Slope Coefficients	Standard Error	*t* value	*p* value	Adjusted R square
Birth weight	Birth weight	-0.003	0.001	-1.9	0.07	
Gestation at birth	**Length of oxygen therapy**	0.05	0.02	2.6	0.015*	
Length of oxygen therapy	**Total visiting hours per week**	-0.4	0.14	-3	0.005*	0.4
Total visiting hours per week						
					*statistically significant (p <0.05)	

Baby's Appearance and Behaviour

1. Demographic Variables Entered	2. Demographic variables in the Final model	Slope Coefficients	Standard Error	*t* value	*p* value	Adjusted R square
Birth weight	Maternal age	0.8	0.5	1.7	0.096	
Gestation at birth	**Highest educational qualification**	10.7	5.2	2.1	0.051*	
Length of NICU stay	**Gestation at birth**	-0.4	0.1	-3.2	0.003*	0.3
Maternal age						
Highest educational qualification					*statistically significant (p <0.05)	
Type of delivery						
Length of oxygen therapy						
Type of oxygen therapy						
Cot or incubator/infantwarmer?						
Length of tube feeding						

Parental Role Alteration

1. Demographic Variables Entered	2. Demographic variables in the Final model	Slope Coefficients	Standard Error	*t* value	*p* value	Adjusted R square
Gestation at birth	**Length of oxygen therapy**	0.1	0.04	2.3	0.03*	
Length of oxygen therapy	**Commencement of oral feeding**	8.2	3	2.7	0.01*	0.33
Cot or incubator/infantwarmer?						
Commencement of oral feeding (Y/N)					*statistically significant (p <0.05)	
Length of tube feeding						
Total visiting hours						

4.2.2 Fathers

Christchurch Fathers

Among the Christchurch fathers, their infant's postmenstrual age and paternal age at the time of the interview were found to be correlated with the stress levels in two of the stress source subscales. Although no associations with any demographic characteristics were found in *Sights and Sounds*, the infant's postmenstrual age was positively correlated with stress levels in *Baby's Appearance and Behaviour* (slope=0.3; t=4.0; p=0.001) and *Parental Role Alteration* (slope=0.2; t=3.2; p<0.005). Paternal age was also associated with the degree of stress in the latter subscale (slope=-0.4; t=-2.2; p<0.05): the younger the father, the higher the stress level. The models explained 34% (the infant's postmenstrual age at the time of study in *Baby's Appearance and behaviour*) and 33% (the paternal age, and the infant's postmenstrual age at the time of study in *Parental Role Alteration*) of variance in the dependent variables, suggesting a reasonable predictive power.

Table 15. Associated Characteristics: Christchurch Fathers (N=30)

Sights and Sounds

1. Demographic Variables Entered	2. Demographic variables in the Final model	Slope Coefficients	Standard Error	*t* value	*p* value	Adjusted R square
Paternal age Cot or incubator/infantwarmer? Other Child(ren) (Y/N)	Paternal age	-0.13	0.1	-1.15	0.26	0.01

Baby's Appearance and Behaviour

1. Demographic Variables Entered	2. Demographic variables in the Final model	Slope Coefficients	Standard Error	*t* value	*p* value	Adjusted R square
Birth weight Gestation at birth Length of NICU stay Postmenstrual age Type of delivery Length of oxygen therapy Commencement of oral feeding (Y/N) Length of tube feeding Other Child(ren) (Y/N) Travelling time from home to hospital Father's total weekly working hours	**Postmenstrual age**	0.3	0.08	3.96	0.001*	0.34
						*statistically significant (p <0.05)

Parental Role Alteration

1. Demographic Variables Entered	2. Demographic variables in the Final model	Slope Coefficients	Standard Error	*t* value	*p* value	Adjusted R square
Birth weight	**Paternal age**	-0.36	0.16	-2.2	0.037*	
Length of NICU stay	**Postmenstrual age**	0.17	0.05	3.2	0.004*	0.33
Postmenstrual age Type of delivery Paternal age Length of tube feeding Total visiting hours						*statistically significant (p <0.05)

Tokyo Fathers

As for the Tokyo mothers, correlations between the demographic characteristics and all three areas of stress were found among the Tokyo fathers. Within *Sights and Sounds,* the Tokyo fathers were more likely to have higher stress when their infants required oxygen therapy for a longer period (slope=0.05; t=2.5; p<0.05). Paternal stress in relation to *Baby's Appearance and Behaviour* was associated with whether or not their babies were allowed to be visited by other people (relevant to the Japanese parents only) (slope=10.4; t=2.2; p<0.05) and with the total period of time of tube feeding their infants required (slope=0.2; t=2.6; p<0.05): they experienced a greater degree of stress when no other people visited their infants and when their infants required tube feeding for a longer period. Regarding *Parental Role Alteration* the duration of tube feeding (slope=0.1; t=3.3; p<0.005) was also positively related to the level of stress for the Tokyo fathers, as were travelling hours from home to hospital (slope=0.6; t=2.2; p<0.05). The findings suggest that the models explained 15% (the length of oxygen therapy in *Sights and Sounds*), and 20% (visiting by others (Y/N), and the length of tube feeding in *Baby's Appearance and behaviour*) in the variance of dependent variables, indicating a minimal predictive power. However, the model in the subscale of *Parental Role*

alteration explained 32% (the travelling time from home to hospital, and the length of tube feeding) of variance in the dependent variables. Additionally, as for the Tokyo mothers, an inconsistent result was found in the *Baby's Appearance and Behaviour* subscale between the backward elimination and stepwise selection methods. The association between ongoing requirement of an incubator (including an infant-warmer) and the stress level was statistically significant (slope=10.8; t=2.1; p<0.05; adjusted R square=0.1) according to the stepwise method. This correlation indicated that fathers whose child (ren) required the incubator/infant-warmer had a higher stress level.

Table 16. Associated Characteristics: Tokyo Fathers(N=30)

Sights and Sounds

1. Demographic Variables Entered	2. Demographic variables in the Final model	Slope Coefficients	Standard Error	t value	p value	Adjusted R square
Birth weight	**Length of oxygen therapy**	0.05	0.02	2.5	0.02*	0.15
Postmenstrual age					*statistically significant (p<0.05)	
Length of oxygen therapy						
Total visiting hours per week						

Baby's Appearance and Behaviour

1. Demographic Variables Entered	2. Demographic variables in the Final model	Slope Coefficients	Standard Error	t value	p value	Adjusted R square
Birth weight	**Visited by others(yes/no)**	10.4	4.8	2.2	0.04*	
Postmenstrual age	**Length of tube feeding**	0.2	0.07	2.6	0.015*	0.2
Paternal age					*statistically significant (p<0.05)	
Type of oxygen therapy						
Commencement of oral feeding (Y/N)						
Cot or incubator/infantwarmer?						
Length of tube feeding						
Travelling time from home to hospital						
Total visiting hours						
Visited by others(yes/no)						

Parental Role Alteration

1. Demographic Variables Entered	2. Demographic variables in the Final model	Slope Coefficients	Standard Error	t value	p value	Adjusted R square
Birth weight	**Travelling time from home to hospital**	0.6	0.3	2.2	0.04*	
Length of NICU stay	**Length of tube feeding**	0.1	0.3	3.3	0.003*	0.32
Paternal age					*statistically significant (p<0.05)	
Length of tube feeding						
Travelling time from home to hospital						
Father's toral weekly working hours						
Total visiting hours						

In addition, one of the Japanese infants presented an extreme value in two characteristics of the infants' required care: the length of oxygen therapy and length of tube feeding, while no such value was found in these characteristics amongst the New Zealand infants. After examining correlations between these two variables and each subscale with and without the outlying value, the linear regression was performed again without the extreme value, for the Japanese fathers only. (This was because the significant change in the correlations was found among the fathers, but not for the mothers. The higher correlations (ranging from r=0.36 to

0.5) were evident at significant levels (p<0.05) in all three subscales when the extreme value was included while correlations decreased to non-significant levels when the value was excluded in the test. This may have had implied that the outlying values had an unjustified influence on the stress scale.) The final models of both the backward elimination and stepwise selection methods were consistent among the three subscales. Interestingly, the infants' birth weight was the only characteristic which had a statistically significant association with all three subscales when the outlying variable was excluded in the regression analysis. Given clinical judgement, the outlying values were included in this study.

4.3 Summary

The demographic characteristics found to be correlated with the degree of stress in each of the three stress subscales differed between the four groups of parents. Despite the differences between the four groups, however, the characteristics related to the infant's medical/nursing care requirements: oxygen therapy and/or tube feeding, were associated with the degree of stress for each of the parents' groups except that of the Christchurch fathers. A difference between the two sites was also identified. The demographic characteristic relating to NICU visiting was associated with the stress level among both groups of Tokyo parents while this was not the case for the Christchurch parents. Interestingly, the infants' and parental characteristics were found to be correlated with the stress level for Tokyo mothers and Christchurch fathers only. The interpretation of these findings is informed by contextual knowledge of the NICUs in Chapter Six: *Discussion*. In the section that follows, parental comments are analysed using a thematic analysis. The findings of this qualitative analysis expand the contextual knowledge of the NICUs and thus enrich the interpretation of the findings of this study.

5. *Individuals' Experience of Parental Stress in NICU: Parental Comments*

In order to gain in-depth understanding of an individual's experiences, which may not be fully addressed in the quantitative questionnaire, all participants were given the opportunity to add their personal comments at the end of the PSS: NICU. Parental comments were collected from 30 parents (19 mothers/11 fathers) in the Christchurch NICU and 17 parents (11 mothers/6 fathers) in the Tokyo NICU (appendix N, O, & P). A thematic analysis informed by a general inductive approach (Thomas**,** 2006), was used for identifying the themes in actual comments of the parents. In this process, particular words and phrases commonly used by the parents were first identified. There were initial key words/phases (59 in Christchurch and 38 in Tokyo) in the parental comments. These key words/phases were then examined for both explicit and implicit contexts so as to code them into categories. The number of

categories created was different between the mothers and fathers in both NICUs: 15 categories for the Christchurch mothers, 10 categories for the Christchurch fathers, and 12 categories for the Tokyo mothers and 9 for the fathers. In addition, although several different categories were found across each group of parents, nine categories for mothers and five categories for fathers were identical between the two units. Finally, it was found that from these categories of each group emerged three main themes – *Uncertainty,* the *NICU context,* and *Communication with staff*, and these themes were the same for the parents of both the Christchurch and the Tokyo NICUs. Table 17 represents the three themes and their applied categories. The cultural backgrounds of the parents and the culture of the NICU settings, including NICU regulations, were different between the two units however, the parental perceptions of their NICU experiences had much in common, as shown below.

Table 17. Three Themes arising from the Thematic Analysis of Parental Comments

Themes	Categories	Tokyo Mothers	Tokyo Fathers
Uncertainty	not being better informed regarding test results/baby's condition	3	3
	uncertainty regarding baby's condition	4	1
	uncertainty related to own health; how to cope after discharge	1	N/A
	wellness of the baby	1	1
	first-time parent - accept the situation as it is	N/A	1
NICU Context	separation	4	N/A
	limitation due to NICU regulations	1	2
	other people/babies in NICU	2	N/A
	people outside of NICU	1	1
	good to be in NICU for the baby's sake	2	1
	external responsibility	N/A	1
Communication	thankful for NICU staff	3	N/A
	trust in nurses enabling accept leveving baby in NICU	1	1
	nurses' comments and attitudes/busy-ness	4	N/A

Themes	Categories	Christchurch Mothers	Christchurch Fathers
Uncertainty	not being better informed regarding test results/baby's condition	4	2
	uncertainty regarding baby's condition	3	N/A
	wellness of the baby	3	1
NICU Context	separation	4	N/A
	unfamiliar NICU physical structure/limitation due to NICU regulations	3	1
	other people/babies in NICU and/or alarms	4	N/A
	people outside of NICU	1	2
	being unsure of role in NICU	2	N/A
	helplessness	1	N/A
	limitations due to own health	2	N/A
	external responsibility	N/A	2
Communication	thankful for NICU staff	7	4
	trust in nurses enabling accept leveving baby in NICU	3	1
	nurses' comments and attitudes/busy-ness	5	1
	inconsistency of nursing care/advice	4	1
	high nursing staff turn-over	3	1

5.1 Uncertainty

Parents dealt with uncertainty throughout their infant's NICU stay. Having knowledge about their infant's condition appeared to be a key aspect that facilitated parental coping abilities. When the parents became aware of the progress that their child (ren) were making and the parents accepted the reality, their anxiety and stress due to being uncertain may well have been reduced. The mothers of both units described their experiences at the beginning of their infant's stay in the NICUs, as below:

> When you give birth to a premature baby, you immediately think the worst. I had no idea that so many premature babies were born and I was really stressed when they took my baby to NICU … The staff in the NICU ward were brilliant. They explained everything … This made the process a lot less stressful as I realised that my baby was in the best place for him, surrounded by people who could help him get bigger and stronger (Christchurch mother).

> When [my baby was] being admitted to the unit, I was anxious about seeing my baby in an incubator, thinking when can my baby come out. … I was worried every day wondering if my baby would grow well. As my baby is gaining weight and feeding well, I have become less worried (Tokyo mother).

However, the parents also experienced situations where they faced difficulties in obtaining knowledge about their infant's condition or required treatment. Reliant on the NICU staff to provide the knowledge that they needed, in particular, the medical or nursing-related information, the parents found that this was not always available. The fathers commented on their experiences:

> I think it is not understandable that no one is able to talk about my child's test results only because my child's team doctors are not present in the unit. The other doctors should tell the parents the results if they are available. This would help relieve us, the parents, from anxiety (Tokyo father).

> The single biggest stress factor for me is the lack of information about progress. Everything I learned I had to get from the information pack given to us on day one. The trouble is when you are working, driving 2 hours a day, and trying to get sleep, you don't have a lot of time to read a pile of information (Christchurch father).

5. 2 NICU Context

The NICU context includes the NICU physical environment, NICU regulations for parents to follow, and inevitable situations arising from the infant's hospitalisation. The parental perception of the NICU context, suggested by the parental comments, was mainly of the unfamiliar, unexpected and sometimes uncomfortable situations the parents faced due to

their infant's NICU hospitalisation. Although there were similarities between the four groups of parents, differences between the two sites, as well as between the gender responses, were evident in key aspects of the NICU context.

5.2.1 Similarities between the two NICUs: The NICU environment and regulations

During the NICU stay, the parents undoubtedly encountered a world that was a completely different world from their own, where they were to follow the many regulations or rules set by the unit. The challenging aspects of NICU environment were illustrated by a parent of each unit:

> Going from level 3, where you have your own space, into level 2 which was exposed to everyone not just a few. This made me feel like I didn't have my own space and the situation was made more daunting knowing that I was going to be there for a long time.... (Christchurch mother).

> Only being able to use a digital camera within a certain time [has been stressful]. This limits the chance to take a good shot of my baby and it is stressful. Although we are allowed to use a disposable camera, the quality of these photos is not good enough, so it has been stressful every time I have got the photos developed (Tokyo father).

5.2.2 Differences between the two NICUs: Mothers' acceptance of NICU admission

The mothers' comments revealed a contrasting perception of accepting NICU admission. Although NICU hospitalisation caused stress in many aspects for the mothers, the Tokyo mothers stated that leaving their baby in the care of others was good for their baby:

> I feel worried about having my baby in the NICU, but, on the other hand, I have been thankful for the situation as I was not ready at all when I had an emergency preterm delivery, and this caused the other stresses that I have had to cope with physically and emotionally (Tokyo mother).

This acceptance appeared to make their stress manageable at the early stage of their infant's hospitalisation. However, this did not seem to be the case for the Christchurch mothers. Their comments implied that they sought their role in caring for their baby during the NICU hospitalisation, and this active participation may have helped them manage their stress. This may have led to further difficulties experienced by the Christchurch mothers:

- Being unsure of my role as a mother in NICU
- Not sure of expectation of hours of being with my child in NICU (Christchurch mother)

5.2.3 Gender differences

Separation:

While no fathers reported difficulties regarding separation, eight mothers experienced difficulties in coping with the separation from their child (ren) necessitated by hospitalisation in a NICU:

> Continuing expressing breast milk even though separated from my child [has been stressful]. I know this is the only thing I can do while I am not with my child, but, I am still worried about the amount I am producing, or I feel guilty when I am not able to get up to express during the night. I feel isolated (Tokyo mother).

> There are some nights that can be very stressful for myself. At first I would alienate myself from my partner and others that live with us. This however didn't help me get over missing my baby. …I know now that its better to talk about my feelings and not bottle them up inside of me (Christchurch mother).

Fathers' perception of their roles during NICU hospitalisation:

Although neither the Christchurch nor Tokyo mothers commented on their external responsibilities, the comments of the fathers implied that they seemed to focus on their role outside of the NICU in order to help their partner and baby. They described the challenges they faced during their infant's NICU stay:

> More stress caused by constant travelling, petrol costs, parking and inability to complete normal household chores, due to being in the hospital (Christchurch father).

> I was struggling and looking for things that I could do. A couple of days later, I came up with the conclusion that the only thing I could do was to work as usual, and leaving the two at the hospital was a good thing for them (Tokyo father).

5.3 Communication with Staff

Communicating with staff seemed to be one of the most important aspects of stress-related experiences among parents in the two NICUs. Several parents in each NICU reported their experiences in a similar way. For example, although the parents stated their appreciation of nursing care/advice offered, they also recalled certain stressful situations relating to particular nurses' comments/attitudes:

> I lost confidence and was hurt by the nurse's comment, 'I will feed your baby next time', as I felt 'I am not doing the right thing for my baby.' Also, I feel upset to see nurses' attitudes when they are feeding babies. … as if they have to do so because of their 'job'. … On the other hand, it was a pleasure to see nurses making special pretty tapes for the NG tube, cutting

> out animal shapes, etc. It makes a warmer atmosphere in the NICU amongst all the medical equipment (Tokyo mother).
>
> … the attitudes and behaviours of some staff can add to the stress of being in NICU. In particular we have had one nurse who seemed to be telling me that I didn't need to be asking questions and she seemed to get annoyed at me. That behaviour makes me feel that I am not important when it comes to my baby's health (Christchurch mother).

On the topic of communication with staff, the Tokyo parents generally referred to specific communication with particular nurses, or the ward's busy-ness:

> When nurses are busy or under staffed I feel afraid to ask about my baby. I wonder if nurses could pay more attention to the parents during visiting hours as it would help us feel more comfortable to ask questions (Tokyo mother).

Whereas the Christchurch parents raised other issues associated with communication with nurses: the frequent nursing staff changes and inconsistent/conflicting nursing care/advice:

> I found that all the nurses have slightly different rules we have to follow and this gets stressful as I'm afraid of being 'told off' for doing the wrong thing. All the nurses are great though and just have different opinions (Christchurch mother).
>
> The amount of staff changes: from day to day and having to get to know different personalities, build up rapport and feeling comfortable questioning new nurses (Christchurch mother).

Lastly and importantly, both Tokyo and Christchurch parents also had common experiences with nurses that led to their positive feelings, therefore facilitating their coping abilities. For instance, the communication with nurses positively influenced the parental acceptance of the situation of having to leave their baby in the NICUs. This suggested that the communication between parents and nurses was fundamental in establishing trust. This is demonstrated in the experiences of the parents described as below:

> The kindness of the nurse's has helped a lot in my understanding of what is being done to my child and therefore it has helped my stress level. …. Knowing that the nurse's are caring for her so passionately is a great relief when I am not @ the hospital (Christchurch Father).
>
> The most stressful thing is that I am not able to be with my son all the time, but I do not feel too stressed as my son's primary nurse and other staff are looking after my son tenderly (Tokyo Mother).

5.4 Summary

Although there were cultural differences between the two NICU environments and regulations, and individual parent's circumstances, three themes were found to be key aspects of parental experiences in both units. *Uncertainty,* the *NICU context,* and *Communication with Staff* were interwoven, suggesting that the communication between the parents and staff was vitally important regardless of the different cultural background. The parental comments described in this section indicate that although the event of NICU admission caused parental stress, the degree and/or quality of communication between the parents and staff was a driver of the stress level of the NICU parents. In other words, despite the other two themes, *Uncertainty* and the *NICU context,* which also emerged, they did not always seem to provoke parental stress in themselves. Parental stress levels may have increased or decreased depending on how they perceived the communication with staff in the NICU setting.

In this thematic analysis, similarities and differences were found between the two NICU environments as well as between responses according to the parents' gender. Although communication between the parents and staff was the key aspect of the stress-related experiences in both units, the circumstances affecting the communication were not always similar. For example, in Christchurch, inconsistency of the nursing advice, due to the number of nurses involved in each infant's care, seemed to influence the level of parental stress. Furthermore, a noticeable difference was found among the mothers in the way of accepting their infant's NICU admission.

Regarding gender differences, the findings were similar for both units. The mothers reported stress mainly in relation to separation from their baby and the NICU environment whereas the fathers' comments suggested that they found their stress lay in their role external to the NICU.

Through the use of a thematic analysis in this section, parental comments have revealed issues not raised in the main questionnaire. Importantly, the three themes: *uncertainty, NICU context and communication with staff*, are merged with the NICU parental experiences illuminated by the quantitative findings. In the light of the relational approach to family nursing, these quantitative and qualitative findings together will facilitate an in-depth understanding of stress-related parental experiences and provide a guide to the essential support for parents who find themselves with infants requiring care in NICU settings. The three themes and other statistical results presented in this chapter, are integrated and discussed together in the final chapter – Chapter Seven: Discussion, which follows.

Chapter Seven: Discussion

This study is based on the assumption that the cultural norms of medical or nursing care environments affect parental stress-related experiences in NICU settings differently in different countries. Recognition of these cultural norms is an important element of nursing practice, as is understanding the context in which practice occurs. In addition to the quantitative analyses, this study provides a qualitative analysis of parental comments to give further insight into parental NICU experiences. Doane and Varcoe's (2005) concept of relational inquiry (See chap. 1.3, pp. 2-7) facilitates an understanding of relationships between the four dimensions of knowledge about parents and their experiences as well as about nurses themselves in each NICU context. The findings of both the quantitative and qualitative analyses, in highlighting the differences and similarities in parental perception of stress-related experiences between the two NICU contexts, illuminate crucial aspects of the nursing role in parental support.

The findings of the quantitative analyses of parental experiences in the two NICU contexts are discussed first. Three principal features of parental experiences in the NICUs identified by a thematic analysis – *uncertainty, NICU contexts,* and *communication with staff* – are integrated into these quantitative findings. In the light of the relational approach to family nursing, the findings are explored from a perspective of multi-dimensional knowledge in a process of relational inquiry to illustrate the nursing role in parental support.

1. *Parental Experiences in the Two Different Cultural Contexts*

1.1 Parental Perception of the Sources of Stress in the two NICUs

Differences between the two NICUs with regard to parental perception of the stress sources specified in the questionnaire, PSS: NICU: *Sights and Sounds*, *Baby's Appearance and Behaviour* and *Parental Role Alteration* are identified in this study. *Parental Role Alteration* was the key cause of stress among the Christchurch parents, whereas *Baby's Appearance and Behaviour* was most likely to cause stress among the Tokyo mothers, and *Sights and Sounds* among the Tokyo fathers. For Christchurch fathers, *Baby's Appearance and Behaviour* was also a key subscale related to stress. The *Parental Role Alteration* subscale has often been the most significant parental stress source as seen in the New Zealand study by Carter, Mulder & Darlow (2007) as well as other previous studies (Dudek-Shriber, 2004; Lau, Hurst, Smith & Schanler, 2007; Melnyk, et al., 2006; Seideman et al., 1997; Shaw, Ikuta & Fleisher, 2006; Preyde & Ardal, 2003). However, in this current study, this was apparent for Christchurch parents only. Indeed, for the Tokyo fathers, *Parental Role Alteration* was the area that produced the least stress. Although in past studies *Sights and*

Sounds has often been reported as the area producing least stress (Carter et al., 2007; Dudek-Shriber, 2004; Foster, Bidewell, Buckmaster, Lees & Henderson-Smart, 2008; Lau et al., 2007; Preyde & Ardal, 2003; Seideman et al., 1997), in this study this subscale was most frequently linked with a higher stress level among the Tokyo fathers. The inconsistency of the findings – of this study and between this study and previous studies – points to the unique and complex circumstances of each NICU in its cultural context.

Parental perception of specific situational experiences within the subscales in the two NICU settings highlights everyday parental experiences in each NICU context (See chap. 6.3, pp. 44-50). In general, of the four groups of parents, the Tokyo mothers considered the largest number of situations stressful, while the Tokyo fathers perceived stress in the fewest situations. Nonetheless, particular stress-related situations shared by both Tokyo mothers and fathers indicate that their stress related directly to their infant's prematurity and/or the severity of their condition which may have required the use of high-tech equipment. For example, the majority of both the Tokyo mothers and fathers experienced stress in connection with sudden alarm noises (*Sights and Sounds*), seeing medical equipment attached to their baby, and witnessing their baby's abnormal pattern of breathing (*Baby's Appearance and Behaviour*). Over half of the Tokyo mothers were stressed by a number of situations within the *Baby's Appearance and Behaviour* subscale that did not cause stress for many of the Christchurch mothers: statistically significant differences, for example, their infants' wrinkles and/or small appearance and inability to cry. These findings relating to the Tokyo parents suggest that their stress and anxiety were likely to have been driven by the infants' medical condition, which may have required the use of high-tech medical equipment. On the other hand, the situations in which the majority of both Christchurch mothers and fathers perceived stress, reflect their experiences in relation to their degree of involvement in the care of their baby. The Christchurch parents experienced stress related to sudden alarm noises (*Sights and Sounds*), and seeing intravenous line insertion (*Baby's Appearance and Behaviour*), and they experienced helplessness towards their baby, being unable to protect their baby from pain, and/or being unable to hold the baby whenever they wanted (*Parental Role Alteration*). Although the perception of both the Christchurch and Tokyo mothers concerning *Parental Role Alteration* was not statistically different, the paternal perceptions regarding two situations in particular in this area were statistically different between the majority of fathers in the two NICUs. These two situations were separation from their baby, and helplessness regarding being unable to protect the baby from pain and painful procedures. The Christchurch fathers expressed feelings of helplessness due to being unable to control the situations in which their baby suffered from pain and/or illness in unfamiliar NICU environments. The situational experiences of the two sets of NICU parents imply inter-

relationships between the three subscales which illuminate general features of stress-related parental experiences in each unit.

These differences in the parental perception of the sources of stress may be due in part to differences in the infants' condition between the two NICUs: the Tokyo infants might have been more clinically unstable than the Christchurch infants. In fact, although the average gestation of the infants at birth was exactly the same (31 weeks and 2 days), their birth weight as well as the percentage requiring respiratory assistance was significantly different (See chap. 6.1, pp. 37-39). This may have been a reason why the Tokyo parents, more than the Christchurch parents, experienced higher stress in connection with their infant's condition. However, these differences might not necessarily reflect the infants' medical condition. As for term infants, the difference in the average birth weight between the two NICUs can also be attributed to racial differences (McCowan, Stewart, Francis & Gardosi, 2004), though such racial difference specific to the birth weight of pre-term infants has not yet been fully researched. In this study, the average birth weight and gestation of those Christchurch infants (n=18) born between 31 weeks 0 days and 34 weeks 6 days were 2085 g (SD=471) and 33 weeks 1 day gestation (SD=1.2), whereas those of the Tokyo infants (n=18) were 1698 g (SD=377) and 31 weeks 2 days gestation (SD=1.2). When looking at the average weight and gestation of this particular gestation group with reference to the infants in the two NICUs, the Christchurch infants presented on the 50th percentile while the Tokyo infants presented on the 10th percentile according to a recent Canadian based pre-term growth chart (Fenton, 2003). These differences may have contributed to the greater use of oxygen therapy for the Tokyo infants, indicating that the Tokyo infants were medically more at risk. In a nationwide Japanese study (Kusuda et al. 2006) which included 2145 Very Low Birth Weight (VLBW) infants, infants weighing between 1251g and 1500g, the average birth weight was 1380 (±72) g, corresponding to the average gestation of 31.8 (±2.4) weeks. Within the lower birth weight group in the same study, ranging from 751g to 1000g, the average birth weight was 883 (±72) g, corresponding to a gestation of 27.9 (±2.2) weeks. In this present study, the average birth weight and gestation in these birth weight groups among the Tokyo samples were consistent with the Japanese data: 1400g and 31.4 weeks gestation in the former group and 875g and 28 weeks gestation in the latter. This may suggest that the smaller size of the Tokyo infants in this study may represent the average size of Japanese pre-term infants. Different distributions of birth weight and/or gestational age are evident in mortality ratios across different targeted populations (Hertz-Picciotto & Din-Dziethem, 1997). Although the lower birth weight of Extremely Low Birth Weight (ELBW) or VLBW infants indicates their increased vulnerability, the mortality and mobility of premature infants are also associated with factors such as gender, race (Morse et al., 2006), and gestation (Kusuda et al., 2006). Therefore, the

differing average infant birth weight between the two NICUs does not necessarily suggest a difference in the infants' medical condition. Regarding respiratory assistance (including intubation, CPAP and oxygen therapy), the total percentage of infants required this was significantly higher among the Japanese infants. The numbers needing intubation or CPAP during NICU hospitalisation was not significantly different: 20 (58%) infants in the Tokyo NICU and 16 (48%) in the Christchurch NICU, though this non-significant result may reflect the relatively small samples in this study. In summary, the differences in the infants' birth weight and the use of oxygen therapy between the two NICUs did not necessarily reflect differences in their medical conditions. Thus, these differences were unlikely to be a source of bias in parental perception of their stress-related experiences.

According to the scoring method (Metric 2) of the PSS: NICU used in this study (See chap. 4.4, pp. 23-25), only those situations actually experienced by parents were highlighted. This is because any situation described by the subscale items that were not experienced by the parents were scored as 1 (one), indicating that the situation did not produce stress. Therefore, the differences in parental perception illuminated in this study may reflect differences in the degree to which parents actually experienced particular situations in each NICU environment. For example, a possible contextual reason why the Japanese fathers perceived the least stress, in particular regarding *Parental Role Alteration*, may become evident when examining their situation in relation to their total visiting hours: 4 hours per week (See chap. 6.1, pp. 42-43). This was less than one fourth of that of the Christchurch fathers. The Tokyo fathers may have been less likely than their Christchurch counterparts to have had time to become involved in the care of their infants or encounter particular stressful situations. For instance, they might never have encountered a situation in which they witnessed the insertion of an intravenous line, a situation which presented a statistically significant difference between the Tokyo and Christchurch fathers. If this was the case, the significant difference may be due to the Japanese fathers having a fewer chances to encounter such a situation than the New Zealand fathers.

Despite the differences, the parents in both Tokyo and Christchurch also shared similar experiences, which signal the importance of parental support regardless of cultural backgrounds. The majority of mothers (over 68% in each unit) shared stressful experiences in regard to their infants' requirement of medical equipment and seeing their baby in pain (*Baby's Appearance and Behaviour)*. Within the subscale of *Parental Role Alteration,* separation was the most stress/anxiety-related situation for many of the mothers (94% of the Christchurch mothers and 80% of the Tokyo mothers). Additionally, over 70% of both groups of NICU mothers perceived the situation in which they were unable to feed their baby as

moderately or highly stressful. Although the Christchurch and Tokyo fathers perceived stress areas differently, the majority of all the groups of parents experienced higher levels of stress in association with sudden alarm noises (*Sights and Sounds*). This was the only situation regarding which a larger percentage of both the Christchurch and Tokyo fathers experienced higher stress. Foster, Bidewell, Buckmaster, Lees and Henderson-Smart (2008) found that parental stress did not differ between parents of the CPAP and headbox infants' groups, and the sudden alarm noise was the most stress-related situation within the *Sights and Sounds* subscales for the parents of the both groups in their study. Sudden alarm noises in the NICU environment may be more likely to be a common NICU feature which frightens parents and/or causes them stress regardless of their differing contexts. Therefore, there are particular features of the NICU care environment which can be shared across cultures. In the discussion that follows, characteristics associated with the three sources of parental stress also highlight the underlying norms of the NICU care environments behind the differing parental experiences in the two NICUs.

1.2 Characteristics Associated with the Sources of Stress in the two NICUs

1.2.1 Mothers

Christchurch Mothers

The findings suggest that Christchurch mothers whose infants were fed orally perceived less stress in relation to *Sights and Sounds*. The commencement of oral feeding indicates the infant's positive progress – their having the strength to feed orally – and consequently the infant may no longer require the use of medical equipment or a monitor. This may explain the experiences of mothers of orally-fed babies related to *Sights and Sounds* in the Christchurch NICU. The Christchurch NICU provides nursing care and support based on the *Baby Friendly Hospital Initiative (BFHI)* which encourages breastfeeding (See chap. 5.5, pp. 33-34). The breastfeeding initiation rate (including mothers who expressed breast milk) was about 95% when the BFHI was first introduced in 2001 in the Christchurch NICU (Bartle, 2005). Hence, Christchurch mothers often experience breastfeeding in the first place as opposed to bottle-feeding. At the stage of commencing oral feeding, maternal involvement in the infant's care may increase, resulting in the reduction of negative feelings of helplessness and thus maternal stress and anxiety, and an increase in coping ability in the NICU environment. The findings of this study underline benefits of nursing support for breastfeeding as well as expressing breast milk in the NICU from an early stage of NICU admission. Encouragement of breastfeeding/expressing breast milk in the NICU setting contributes not only to the physiological wellness of infants and mothers but also to maternal coping ability and the lessening of maternal stress/anxiety during NICU hospitalisation (Auscott, Donohue, Atkins

& Allen, 2002; Kavanaugh, Meier, Zimmermann & Mead, 1997; Lau, Hurst, Smith & Schanler, 2007).

Similarly, the period of time infants required tube feeding was associated with maternal stress in *Baby's Appearance and Behaviour* subscale. In the Christchurch NICU, tube feeding is a primary source for topping up after breastfeeding (chap. 5.5, pp. 32-33). In this study, nearly 60% of the infants required tube-fed top-ups as compared to 9% who were bottle-fed top ups after breastfeeding. Another 30% relied on tube feeding only (See chap. 6.1. pp. 37-39). Thus, the results suggest that the longer period of tube feeding reflected the vulnerability of those infants who relied on tube feeding only, and/or possible on-going issues in regard to establishing breastfeeding. Espy and Senn's (2003) study indicates that preterm infants who are medically at risk are less likely to be breast-milk fed as opposed to formula-milk fed and mothers of those infants were more likely to have difficulties in maintaining breast milk supply during NICU hospitalisation. Previous data in the NICU under study (Bartle, 2005) indicated that the percentage of fully breastfed infants at the time of discharge was lower in younger gestational age groups when comparing infants who were born between 23 weeks and 36 weeks gestational age. In the Christchurch NICU, on-going breastfeeding assessments continue until the infant's discharge and the introduction of bottle-feeding for topping up is often considered prior to the discharge (See chap. 5.5, pp. 33-34). A recent study by Silberstain et al. (2008) found associations between feeding difficulties among premature infants and their neurobehavioural development as well as maternal feeding behaviours during the transition to oral feeding. The needs for continued tube feeding which accounted for an increase in maternal stress in the area of *Baby's Appearance and Behaviour* may indicate maternal experiences of difficulties in establishing breastfeeding in preparation for the infant's discharge.

For the Christchurch mothers, no associations with the demographic characteristics were found regarding the *Parental Role Alteration* subscale, which proved to be the greatest stress subscale. In addition it should be noted that the predictive power of associated characteristics with these stress subscales was not found to be strong (below 20%) in the other subscales (*Sights and Sounds* and *Baby's Appearance and Behaviour*). This may be due in part to the relatively small samples used in this study.

Tokyo Mothers

For the Tokyo mothers, shorter total hours of NICU visiting (per week) and longer duration of oxygen therapy related to higher maternal stress levels regarding *Sights and Sounds*. To the author's knowledge, the relationship between parental stress and time spent in

the NICU has not been investigated by any other studies of parental stress in NICU settings. One study (Carter, Mulder & Darlow, 2007), however, found that previous NICU admission was associated with lower maternal stress in this stress area. Thus, stress derived from the unfamiliarity of the NICU physical environment may be alleviated by the amount of time spent in the unit. In this study, the mean total hours of the Toyo mothers' NICU visiting was 10 hours (SD=5.3) per week. The fixed parental visiting hours of the Tokyo NICU allow for a daily total of 4 hours in the intensive care nursery and about 6 hours in the level II/I nursery (See chap. 5.6, pp. 34-35). Therefore, it is safe to assume that those mothers whose infants required intensive care would have had fewer visiting hours than mothers whose infants were in the level II/I nursery. Accordingly, these mothers, whose infants were in a more vulnerable state, would have been less used to the NICU physical environment due to the limited amount of time they spent in it. However, the fixed visiting hours alone might not have limited the maternal visiting. For example, 77% of the Tokyo mothers had Caesarean section: postnatal condition may be likely to influence maternal visiting in NICU settings. Nevertheless, although the reasons for restriction of NICU visiting may vary among the Tokyo mothers, the NICU visiting regulation can further limit access to the NICU for them, resulting in an increase in maternal stress in relation to *Sights and Sounds* in the NICU environment.

Similarly, the association between the infants' longer requirement of oxygen therapy and maternal stress in *Sights and Sounds* points to a correspondence with the degree of severity of the infants' condition. When the infants here under study required oxygen therapy, they were more likely to have been reliant on high-tech medical equipment in the intensive care environment. Maternal stress related to *Sights and Sounds* may thus have increased for the mothers of these infants because of their experience of being in such an unfamiliar environment. This finding also suggests that the NICU physical environment was more likely to provoke maternal stress when the infants required prolonged medical treatment. In other words, the Tokyo mothers whose infant was medically more fragile than the others may have never become used to the environment even after being in the NICU for a longer period because of their infant's condition.

Associations with maternal educational backgrounds and infants' gestational age were found in relation to maternal stress and anxiety within the *Baby's Appearance and Behaviour* subscale, the greatest area of stress for the Tokyo mothers. Although parental educational backgrounds have been included in studies investigating parental stress using PSS: NICU, the effects of the educational level have not been apparent in the subscale *Baby's Appearance and Behaviour* (Carter, Mulder & Darlow, 2007; Dudek-Shriber, 2004; Lau, Hurst, Smith & Schanler, 2007). In other studies, less maternal education was found to be related to anxiety

(Zelkowitz, Bardin & Papageorgiou, 2007) and depressive symptoms (Davis, Edwards, Mohay & Wollin, 2003). The greater stress in relation to *Baby's Appearance and Behaviour* among the Tokyo mothers who had lower educational levels may indicate developing depressive symptoms. In other words, this study might have included serious cases of psychological distress among mothers who may have required attention. However, due to the different educational systems of the countries in which past studies investigating parental stress were conducted (USA, New Zealand, Canada and Australia), educational qualifications were categorised and interpreted differently. The educational categories of this study also differ from the categories used in past studies: all the participants had at least 12 years of education whereas the previous studies included less than 12 years. Therefore, the findings of this study may not reflect the hypothesis that the study included mothers who possibly suffered from psychological distress, and the inconsistency of the results with these past studies using PSS: NICU may also have been due to methodological or sampling differences. Further investigation regarding the relationship between maternal education backgrounds and stress/anxiety is required, particularly regarding the Japanese socio-cultural context.

Infants' gestation at birth was also associated with stress of the Tokyo mothers in the *Baby's Appearance and Behaviour* subscale. This finding is consistent with past studies by Dudek-Shriber (2004), and Mulder and Darlow (2007). Due to their prematurity, infants (particularly ELBW or VLBW infants) are more likely to suffer from a life-threatening event following birth and/or rely on high-tech medical equipment or prolonged medical treatment (Kusuda et al. 2006; Morse et al., 2006). These situations related to prematurity may have a strong impact on maternal stress. Zelkowitz, Bardin and Papageorgiou (2007) found that although the medical condition determined by a neurobiological assessment tool had no association with maternal stress, the prematurity of the infants was related to anxiety. Therefore, the findings of this current study may imply that the Tokyo mothers struggled with uncertainty, for example, being unsure of their baby's future well-being, regardless of whether or not their infant had medical complications.

For the Tokyo mothers, commencement of oral feeding and the length of oxygen therapy were related to maternal stress in *Parental Role Alteration*. In the Tokyo NICU, unlike the Christchurch NICU, starting oral feeding as well as transferring from an incubator to a cot is timed according to the infants' postmenstrual age. At the time of commencement of oral feeding, if the infants are medically stable, they are transferred to a cot. For the Tokyo mothers, involvement in their infant's care including bottle-feeding/breastfeeding their baby, changing, or bathing increased at this time (See chap. 5.6. pp. 34-35). Increased care involvement according to NIDCAP fosters a sense of closeness between mothers and their

babies, with eye contact being attributed to bonding (Kleberg, Hellström-Westas & Widström, 2007). For the Tokyo mothers, at this stage of commencement of oral feeding, the mothers might have been able to realise their baby's positive progress through their experiences of caring for him/her, and establish their role as parents in the NICU. By contrast, when infants required an incubator and/or tube feeding due to their prematurity or medical condition, the NICU routine nursing care might have allowed only limited maternal involvement in the care of their infants. Similarly, a shorter length of oxygen therapy was associated with less stress in relation to *Parental Role Alteration*, implying that the infants' medical condition probably affected maternal perception of their role as mothers. An association between infants' medical condition and maternal stress in this area was also reported in the study by Dudek-Shriber (2004). The two associated characteristics: commencement of oral feeding and the length of oxygen therapy, may suggest that the Tokyo mothers felt helpless because they perceived they could not do anything for their baby when their baby relied on nursing and medical care.

1.2.2 Fathers

Christchurch Fathers

Among Christchurch fathers, an older postmenstrual age of the infant was associated with higher levels of paternal stress in relation to *Baby's Appearance and Behaviour.* At the time of their participation, the mean postmenstrual age of the Christchurch infants was 35 weeks and 2 days (mean gestation at birth was 31 weeks 2 days), and the mean length of their NICU stay was 29 days (See chap. 6.1, p. 37). Past studies in regard to paternal stress and anxiety have often included the length of NICU hospitalisation in their analysis (Melnynk et al., 2006; Shaw, Ikuta & Fleisher, 2006; Zelkowitz, Bardin & Papageorgiou, 2007), but the infant's postmenstrual age has often been excluded. In Dudek-Shriber's study (2004), a longer length of NICU stay and a cardiovascular diagnosis were found to be associated with parental stress regarding *Baby's Appearance and Behaviour*. However, in the case of studies such as this one which are conducted during the NICU hospitalisation, not after, the results do not reflect the significance of the length of NICU stay, since at the time of their participation those infants who require long hospitalisation might only be at the beginning of their NICU stay. A negative psychological influence on parents due to infants' medical complications and/or the degree of required intensive care has not been supported in other studies (Foster, Bidewell, Buckmaster, Lees & Henderson-Smart, 2008; Zelkowitz et al., 2007). However, factors relating to the prematurity of the infants – birth weight and/or gestation at birth – have consistently been found to be associated with parental stress (Dudek-Shriber, 2004; Mulder & Darlow, 2007; Zelkowitz et al., 2007). It is likely that the association between an older postmenstrual age of the infant and greater paternal stress found in this study suggests that the

fathers' stress had increased during the course of the NICU stay. Their infants had probably been born at a younger gestation, thus they had spent longer in the NICU and paternal stress had increased accordingly.

The older postmenstrual age of the infant was also positively correlated with paternal stress related to *Parental Role Alteration*. As suggested above, an older postmenstrual age might have reflected a longer NICU stay due to the infant's prematurity. With regard to *Parental Role Alteration*, one implication is that the findings may indicate a specific developmental stage of infants at which paternal stress increases during the course of the NICU stay. Infants' physiological and neurological development is assessed by their postmenstrual age (Als et at., 2004; Auscott, Donohue, Atkins & Allen, 2002; Woodward, Mogridge, Wells & Inder, 2004). Although in the Christchurch NICU oral feeding, often breastfeeding, was introduced according to the infants' cues (See chap. 5.5. pp. 33-34), the postmenstrual age at the introduction to oral feeding might have been predictable due to the infants' neurobehavioural, oromotor development (Als et al., 2004; Auscott et al., 2002). As the infants grew, the fathers may have become increasingly involved in their infant's care in the NICU. The average length of NICU stay was 15 days (at 36 weeks of postmenstrual age) among infants who were born at 34 weeks gestation at Christchurch NICU in 2007 (See chap. 4.6, p. 26). As this study was conducted post-acute period of the infants' NICU hospitalisation, an older postmenstrual age of the infant may indicate paternal stress-related situations in the later stage of the NICU stay which is likely to be in the process of preparing for the infants' discharge. A study by Auslander, Netzer & Arad (2003) found that parental anxiety is evident post-discharge and the level of anxiety is similar between mothers and fathers. Characteristics associated with the anxiety are different, however, indicating that mothers and fathers perceive issues differently. The findings of this study show that both Christchurch mothers and fathers alike experience a rise in stress level during the last stage of their infant's NICU stay.

With regard to *Parental Role Alternation,* Dudek-Shriber (2004) found an association between higher levels of paternal stress and young parental age. As the author stated, younger fathers are more likely to be first-time fathers. In this current study, the mean age of the Christchurch fathers was 35 (SD=7) and about 45% of the Christchurch parents had other child (ren), most of whom lived with the parents. Entering into fatherhood involves enormous psychological challenges: taking on new responsibilities, facing possible relationship changes with their partner, and learning how to care for their infants (Barclay & Lupton, 1999; Deave & Johnson, 2008). These challenges would be all the greater for young fathers when having to experience the transition to fatherhood within a NICU setting.

Tokyo Fathers

As for the Tokyo mothers, the length of oxygen therapy the infants required was associated with stress for the Tokyo fathers in relation to *Sights and Sounds*. Again, this may imply stress caused by the infants' medical condition and the increased likelihood of stress due to being in a high-tech medical environment. This also suggests that for the Tokyo fathers the situation in which the infants required oxygen therapy was worrying and difficult to adjust to and that paternal stress was likely to increase with time in the intensive care environment.

Within the *Baby's Appearance and Behaviour* subscale, NICU visiting regulations as well as the length of time infants required tube feeding were associated with stress among the Tokyo fathers. In the Tokyo NICU, other family members were allowed to see the infants through a specially designed window in the level II/I nursery only once the infants had been transferred from the intensive care unit (See chap. 5.6, pp. 34-35). At the time of this study, about 60% of the Tokyo infants had been transferred to a cot, and nearly 70% of those infants were visited by relatives apart from their parents (See chap. 6.1, pp. 38-39 & p. 42). Therefore, the findings related to the NICU visiting regulations most likely reflect the paternal stress of having an infant in intensive care, compounded by having no other family members visiting their child at the NICU. In other words, NICU visiting-related regulations involved at a certain stage of NICU hospitalisation shaped the experiences of the fathers whose babies required intensive care.

In the Tokyo NICU, transferring from tube feeding to oral feeding usually proceeded according to the infants' postmenstrual age (See chap. 5.5, pp. 33-34). Therefore, the length of time infants required tube feeding may also have indicated the infants' prematurity or medical condition. Infant's prematurity was found to be related to parental stress and anxiety in past studies (Zelkowitz, Bardin & Papageorgiou, 2007). If this is the case, the fathers might have acknowledged their infant's progress in relation to *Baby's Appearance and Behaviour* according to whether or not their infant required tube feeding, and thus a prolonged requirement of tube feeding would have increased stress and anxiety among the Tokyo fathers.

For the Tokyo fathers, a longer requirement of tube feeding was also associated with stress in the *Parental Role Alteration* subscale, along with the travelling time from home to hospital. As suggested earlier, the length of time infants required tube feeding implied the physiological and developmental growth of the infants according to their postmenstrual age or their medical condition. In the Tokyo NICU, parental involvement increased after the infant's transference to a cot and this might have coincided with the transition from tube feeding to oral feeding (See chap. 5.6, pp. 34-35). Therefore, the longer period of tube feeding probably

reflected a particular stage in the course of NICU hospitalisation in which the Tokyo fathers were less involved in the care of their infants. Lindberg, Axelsson and Öhrling (2007) highlighted fathers' willingness to be included in the care of their infants and to be informed regarding the on-going progress of their premature infants. Similarly, Sweet and Darbyshire (2008) found that although fathers support breastfeeding for their premature infants, they are also keen to engage with their baby while bottle-feeding. Involvement in feeding their own child is an important, 'symbolic' experience for fathers (Barclay & Lupton, 1999, p.1016). The Tokyo fathers might have felt helplessness and loss of control due to what they perceived as limited involvement in the care of their baby when their infants required tube feeding.

Travelling time from home to hospital was also related to paternal stress in *Parental Role Alteration.* This may reflect the Tokyo fathers' perception of their own role during their infant's NICU hospitalisation. Advocating for the infants and their mothers has been found to be important to the NICU fathers, indicating the possible difficulties in coping with both their social responsibilities and family in the unexpected circumstances (Lindberg, Axelsson and Öhrling, 2007; Sloan, Rowe & Jones, 2008). In this study, all the Tokyo fathers were in employment, and their average working hours were 54 hours per week: this was negatively correlated with their total NICU visiting hours (See chap. 6.1. pp. 42-43). They spent about 2 hours travelling from home to hospital and back again, and the fathers who spent more time travelling had higher stress levels in relation to *Parental Role Alteration.* This might suggest that these fathers faced time-constraints while trying to balance their role as fathers with their social responsibilities.

For the Tokyo fathers alone, the regression analysis was repeated due to the influence of outlying values related to a prolonged length of time an infant required tube feeding and oxygen therapy on the stress scale (See chap. 6.4, p.57). When these outlying values were excluded from the analysis, the infant's birth weight was found to be the only characteristic responsible for stress among the Tokyo fathers. This may imply that when the infant required NICU hospitalisation for a longer period, increased paternal stress was associated with the on-going requirement for medical and nursing care treatment rather than with the infant's weight at birth. This might indicate that when the NICU stay is longer the fathers may judge their infant's wellness by seeing them feeding orally, not by looking at their infants' birth weight. In this way, the fathers might acknowledge the progress of their infants through on-going nursing and medical care as time passes. This study indicates that the required period of feeding via tube and/or oxygen therapy became a measurement for the Tokyo fathers to identify the stage of their infant's progress. In addition, the predictive power of associated

characteristics with the three stress subscales was not found to be strong (below 20%). This may be due to relatively small samples used in this study.

1.3 Summary

One of the main findings in this study is that the three sources of parental stress are interrelated: *Sights and Sounds*, *Baby's Appearance and Behaviour,* and *Parental Role Alteration*. The infant's condition was found to be responsible for the situations which caused the Tokyo parents higher levels of stress in all three stress source subscales. On the other hand, the change in parental role and limited involvement in the infant's care was responsible for the Christchurch parents' greater stress-related experiences in all three stress subscales. Interestingly, among the four parents' groups, the Tokyo mothers considered the largest number of situations stressful, while the Tokyo fathers perceived stress in the fewest situations. However, the Tokyo fathers felt most stress in the *Sights and Sounds* subscale, which all other parents' groups perceived as the least stressful area, suggesting that the shorter visiting hours of the Tokyo fathers were responsible for this finding. On the other hand, there were several stressful situations commonly experienced by the two sets of NICU parents: for the mothers these were in relation to the change of parental role and for the fathers, sudden alarm noises.

The demographic characteristics related to the infant's medical/nursing care requirements – oxygen therapy and/or tube feeding – were associated with high degrees of stress for each of the parents' groups except that of the Christchurch fathers. The NICU visiting-related regulations were associated with the stress level among both groups of Tokyo parents while this was not the case for the Christchurch parents. Additionally, the infants' and parental characteristics were found to be associated with stress level for Tokyo mothers and Christchurch fathers only. These differences highlight the norms of the NICU care environments underlying the differing parental experiences in the two NICUs. In the Christchurch NICU, both mothers and fathers alike experienced a rise in stress level during the last stage of their infant's NICU stay in relation to their involvement in the infant's care, including establishment of feeding orally. In the Tokyo NICU, on the other hand, higher levels of parental stress were likely to be related to the infants' condition and the duration of intensive care required, when parental involvement might have been limited. These findings indicate key aspects of parental support in different cultural NICU contexts. An in-depth discussion of the nursing role in supporting NICU parents, guided by the relational approach to family nursing – *how* nurses can best support the parents – now follows.

2. *The Nursing Role in Parental Support: the Relational Approach to Family Nursing*

As seen in the previous section, cultural norms in NICU care environments influenced parental experience. In the quantitative analysis, these differences in parental experiences in both NICUs resonate with the three themes: *uncertainty, NICU contexts,* and *communication with staff*. These three themes reflect the importance of the relationships between parents and nurses, and between parents and their environments. Doane and Varcoe (2005) emphasise that knowing families in relation to their contexts is the basis of understanding their needs and concerns in nursing practice. The process of understanding families involves nurses reflecting upon themselves in their own contexts as well as upon the contexts which they and families are shaping at any given moment. As discussed in Chapter 1.3 (See pp. 2-7), there are important elements in relational inquiry, which are outlined in Table 18.

Table 18. Key Elements of Relational Approach to Family Nursing

Four types of Relational Inquiry	Key words	Key questions	Eleven Skills of Relational Inquiry
Empirical Inquiry	1. Scientific knowledge 2. Personal knowledge 3. Subjective and Objective knowledge	What is significant for the family, and what do they want to know?	1. Entering into relation: getting 'in sync' with a family 2. Being in collaborative relation: staying 'in sync' 3. Inquiring into the family health and healing experience 4. Following the lead of families 5. Listening to and for 6. Self-observation 7. Pattern recognition 8. Letting be and change 9. Collaborative knowledge development 10. Naming and supporting capacity 11. Emancipatory action
Contextual Inquiry	Relationships within and between 1. Self 2. Others 3. Contexts	What have we brought here, in this given context?	
Ideological Inquiry	1. Taken-for-granted ideas 2. Habitual ways of thinking 3. Beliefs and values	What do we unconsciously do in a particular context, and how does it affect families?	
Ethical Inquiry	1. Decision-making 2. Autonomy and being in-relation 3. The best nursing practice	What do we think is good, and for whom are we doing good?	

In examining the three themes, the importance of the nursing role in parental support is explored from the perspective of relational inquiry: empirical, contextual, ideological and ethical. The eleven skills of relational nursing practice (See chap. 1.3, pp. 4-5), pivotal to the

process of relational inquiry are also identified as the essential elements of the nursing role. These relational skills appear in *italics* in the discussion. Although the four types of inquiry overlap one another, they are addressed accordingly in relation to each of the three themes in the discussion that follows.

2.1 Uncertainty

The findings reveal that parents of both NICUs dealt with uncertainty regarding their infants' condition throughout hospitalisation. Doane and Varcoe (2005) point out that nursing practice often focuses on a single explanation for health-related issues in order to reduce uncertainty. Consequently, nurses are likely to depend on objective information about patients/families, and often focus on tracking down specific problems that can be explained objectively (Doane & Varcoe, 2005). In this current study, parents' willingness to have empirical information regarding their infant's medical condition and required treatment is apparent, indicating that parental stress and anxiety may increase when parents' attempts to obtain the information are hindered. Parental stress is most likely to relate to the infant's condition among the Tokyo parents, and particularly, younger gestation at birth was associated with greater stress for the Tokyo mothers. In the parental comments, parents in both units commonly reported stressful, uncertain situations in relation to a lack of information regarding their infant's condition. In response to parental questions regarding their infant's condition and/or required nursing care, nurses may try to search for empirical answers. Nonetheless, when focusing on certain, objective matters only, nurses will fail to realise families' real concerns behind their questions related to empirical information (Doane & Varcoe, 2005). In the relational approach, empirical inquiry not only pays attention to the biomedical aspects of a patient's condition, but also to a wide range of empirical knowledge, including the concerns of the family. This approach directs nurses to explore the patient's condition from different angles in each unique context (Doane & Varcoe, 2005). In order to understand parents' real concerns, and offer valuable parental support, one of the most important actions is a key relational skill, *listening to and for*. When nurses open up to parents and learn the experiences of the parents through listening, they will be better able to respond to the parents' main concerns.

The parents' patterns of dealing with uncertainty are also identified in the findings. For instance, a possible reason why the length of time infants required oxygen and/or tube feeding was associated with the levels of parental stress among the Tokyo parents may be because parents acknowledge their infant's progress through observing the changes in their care requirements. The mothers in both units recalled the uncertain, stressful situation in which their baby was admitted to the NICU – not knowing what caused their baby's premature

delivery – but they also stated that their stress and anxiety were reduced when they recognised their baby was thriving, through their observation and/or dialogue with nurses. For the Christchurch mothers, the findings suggest that the commencement of oral feeding is significant to them as an indicator of their infant's progress. Recognising the parental experience of being uncertain is, for nurses, the first step towards awareness of parents' coping patterns (*pattern recognition*). With this understanding, nurses are able to respond to parents' empirical concerns related to the test results and/or required medical and nursing care for their infants in meaningful ways. This means, for example, not focusing only on problems to solve with empirical information but also on broader parental concerns. This response is not only directed by nurses' own nursing knowledge but is also guided by knowledge of the families, through *listening to* them and *listening for* their concerns. Doane and Varcoe (2005) state that the empirical inquiry leads into other forms of inquiry – contextual, ideological and ethical – as the families and nurses *collaborate to develop their knowledge* to deal with uncertainty. For the NICU parents, nurses are the main providers of their much-needed information during the NICU stay (Kleberg, Hellström-Westas & Widström, 2006; Melynk et al., 2005; Sloan, Rowe & Jones, 2008). *Listening to* the parents is a vital role for nurses in providing parental support which is responsive to the parents in the multifaceted NICU context.

2.2 NICU contexts

In this study, the NICU context refers to the NICU physical environment, regulations, medical and nursing care, and inevitable situations arising from the infant's hospitalisation. Understanding the relationships between parental experiences and the NICU contexts is integral to fostering parental support. The findings demonstrate the differing contextual influence, in relation to the NICU regulations and nursing care, on parental experiences. For instance, in the Tokyo NICU particular times of the day for parental visiting were limited and fixed, and this might well be one reason for the differences between the two NICUs with regard to the total visiting hours, not only of the fathers but also of the mothers. The findings also suggest the association between the total NICU visiting hours and maternal stress in *Sights and Sounds*. Differing visiting hour regulations – just one example of the norms of medical and nursing care environments – are likely to have shaped the experiences of the parents, and thus their perception of stress, in each of the two NICU cultural contexts. This in turn illustrates that nurses work in different cultural NICU care environments which may determine their experiences of providing parental support. For the Tokyo nurses, for instance, the visiting regulation might limit their time to communicate with parents individually as all the parents visit the NICU within the same timeframe. This may also make it more difficult for nurses to learn about parents through *pattern recognition.*

In contextual inquiry, as in other forms of inquiry, in order to recognise the needs of families, it is essential to consider and understand contextual influences on the experiences of both families and nurses and their capabilities of dealing with difficulties (Doane & Varcoe, 2005). The parental comments in both the Tokyo and Christchurch NICUs illustrate the challenging experiences of the parents in relation to the NICU regulations, suggesting possible constraints on the capabilities of the parents in the NICU care environments. Recognising possible contextual constraints on nursing practice is also important, in order to enhance their practice in parental support. For example, the Australian study of Chia, Sellick and Gan (2006) found that ward busy-ness and insufficient nursing protocols hindered the encouragement of Kangaroo care[8], suggesting the needs for further development of nursing education in practice. Paying attentions to contextual influences lead to further nursing consideration, and this awareness may facilitate nurses' ability to recognise concerns and experiences of parents who find themselves in the NICU. When nurses question how their NICU context shapes their capacity to respond to parents' need, and what circumstances constrain their approach to the parents, they will be able to step forward to *enter into relation: get 'in sync' with a family,* to listen to the parents and to develop knowledge together with the parents in their challenging situation.

While drawing attention to the contextual complexity of the two NICUs, this study also highlights the different focus required for parental support during the post-acute stage of the infants in NICU. For example, with regard to differences between the Christchurch and Tokyo fathers, the level of stress in *Parental Role Alteration* was associated with the infant's postmenstrual age for the Christchurch fathers, while it was associated with the infant's prolonged requirement of tube feeding for the Tokyo fathers. These findings signify the importance of supporting paternal involvement in the infant's care (See chap. 7.1, pp. 65-77). Despite both the Christchurch and Tokyo fathers requiring more support during the post-acute stage of NICU hospitalisation, the findings indicate that differing nursing support can shape parental experiences differently throughout the infant's NICU stay. For example, only minimal paternal involvement may be expected from the Tokyo fathers until the later stage of the NICU stay, once their infants no longer require tube feeding. In comparison, parental involvement is expected from the Christchurch fathers right from the beginning of their infants' hospitalisation, and the expectation of increased participation in their infant's care during the latter stage of NICU hospitalisation may present a challenge for the Christchurch fathers, resulting in an increase in paternal stress. This may indicate that supporting the

[8] Kangaroo care is used for optimising parent-infant skin-to-skin contact: the parent holds his/her baby in upright position against his/her chest (Chia et al., 2006).

fathers in their care involvement is necessary for each NICU throughout the infant's hospitalisation, in a way, *naming and supporting the capacity* of the fathers. Sloan, Rowe & Jones (2008) suggest that the degree of paternal stress decreases during the course of NICU hospitalisation when the infant's condition is medically stable, indicating that the fathers develop coping strategies based on their earlier stressful experiences. Similarly, Pinelli (2000) shows that sufficient parental support is key for driving positive family adjustments to the acute-phase of NICU admission, highlighting the importance of parental support at the beginning of the infant's NICU hospitalisation and its possible impact on parental experiences throughout the NICU stay. Paying attention to the accumulative nature of parental experiences, both positive and negative, can foster nurses' responsiveness to the parents' diverse and complex needs. For instance, the routine way of supporting fathers in each NICU may in fact be responsible for increased paternal stress at the later stage of their infants' hospitalisation. In order to recognise changing parental needs during the course of NICU hospitalisation, it is necessary for nurses to reflect on how routine ways of supporting parents influence the experiences.

As part of a relational approach, ideological inquiry sets out to recognise dominant ideologies in the NICU settings and examine how they shape nurses' perceptions, norms and values (Doane & Varcoe, 2005). A relational approach underlines the importance of *self-observation* (Doane & Varcoe, 2005, p.204) in relation to nurses' own perception of families' concerns. This self-observation leads to the recognition of possible problematic assumptions which may inform nurses' habitual ways of thinking in their practice and become norms of the NICU culture in each setting (Doane & Varcoe, 2005). With regard to the aforementioned example of supporting paternal involvement in the infants' care, the findings imply that in each NICU a 'taken-for-granted truth' (Doane & Varcoe, 2005, p.18) of nursing support blinds staff to the fact that a valued, routine way of supporting the fathers can actually be the cause of paternal stress. Indeed, barriers to nurses' responsiveness to parental needs might arise when they are fixed in their ideas regarding good nursing intervention and provide the particular intervention unquestioningly. A Canadian study by Graves and Hayes (1996) points out that nurses might often omit the parental perspective when assessing parental needs, and they are likely to focus on the deficits of parents, resulting in an unsuccessful nursing intervention. Ideological inquiry requires nurses to critique their own values, beliefs, and the way their ideologies shape and are shaped by being in a particular nursing context, since these ideologies possibly interfere in their practice with their understanding of the families and the families' concerns (Doane & Varcoe, 2005).

The parental comments in this study illuminate that the fathers from both countries struggled to balance their role in NICU with their external responsibilities during their infant's hospitalisation. Issues related to external responsibilities were reported by the fathers only, reflecting a gender difference in the parental response to NICU experiences. The mothers, on the other hand, presented contrasting attitudes towards their infant's NICU admission: the Tokyo mothers accepted having to leave their baby in the NICU, in the knowledge that it was good for their baby, whereas the Christchurch mothers sought out their role in the NICU in their process of acceptance. These differences mirror the diverse parental coping patterns in the NICU, illustrating that the parents too 'live in multiple contradictory taken-for-granted ideas' (Doane & Varcoe, 2005, p.281). Despite the contextual constraints of NICU hospitalisation, the parents have the capacity to deal with difficulties in many different ways. However, nurses' taken-for-granted ideas regarding routine parental intervention, for example, might hamper their recognition of the capacity of the parents. The coping patterns of the parents are diverse and one *good* way of supporting the parents may not necessarily be relevant for every parent. For nurses, *self-observation* of their own values and beliefs in their practice opens them up to listen to the parents, and to recognise the parents' strategies to manage difficult situations. Doane and Varcoe (2005) emphasise the importance of supporting and understanding parents' thoughts rather than facilitating families to change themselves. Reflecting on the dominant ideological values in the NICU will encourage nurses to take meaningful actions within the NICU context. What is more, nurses can play an important role in advocating the parents, whose ideologies might be overlooked amongst the dominant NICU ideologies.

2.3 Communication with Staff

It is clear from the findings that communication between the parents and NICU staff is vital to parental support in both NICUs, signifying the crucial role of nurses in ensuring successful communication. Possible underlying issues related to parent-nurse communication may in part be rooted in the NICU's cultural norms in relation to the parental role in decision-making. A British qualitative study (Alderson, 2006) claims that undeveloped, ambiguous ethical nursing practice constrains formal parental involvement in any nursing care-related decision-making even though the parents have clear ideas regarding feasible ways of feeding their baby and timing for discharge. In the current study, both the Christchurch mothers and fathers reported stress-related experiences related to inconsistent nursing advice and/or a high staff turn-over: they found it difficult to know what they should do in the care of their infant and/or how to establish a rapport with staff. These comments were made by the Christchurch parents only, and this may be due to the relatively large number of nursing staff in the Christchurch NICU compared to the Tokyo NICU. In the Tokyo NICU only half of the

number of nursing staff are employed although the NICUs accommodate a similar number of beds (See chap. 5.1, p. 29; 5.4, pp. 32-33). In addition to these differences, the nursing care models used in each NICU may have also influenced parental experiences differently in relation to the number of nurses involved with the parents. Continuity of infants' care is maintained by allocating the same patients to each nurse from shift to shift in the Christchurch NICU, while it is maintained by primary nursing in the Tokyo NICU (See chap. 5.5, pp. 33-34). These differences illustrate the contextual influence on communication and thus on parental opportunity to take part in day-to-day decision-making regarding the infants' care in each NICU. Nurses' moral awareness of the way in which they make their own decisions regarding the infants' care may help them realise that the parents have possibly been given contradictory advice on every different shift. In the relational approach, ethical inquiry guides nurses to ask themselves: 'What are this family's worries?' (Doane & Varcoe, 2005, p. 266). This leads to meaningful communication between the parents and nurses as well as provision of the best ethical nursing practice.

Although the findings highlight the importance of communication, this study utilises the modified version of the PSS: NICU, from which the stress subscale in *Communication with Staff* was excluded after revision (Miles, 2002). Researchers (Carter, Mulder & Darlow, 2002; Dudek-Shriber, 2004; Melyink et al., 2006) investigating NICU parental stress using the original version of the PSS: NICU commonly reported the communication subscale to be the least stress associated area. There is also the possibility of parents being reluctant to criticise nurses during their infant's NICU hospitalisation, a possibility which has been considered in past quantitative studies related to parent-nurse communication in NICU settings (Davis, Edwards, Mohay & Wollin, 2003; Dudek-Shriber, 2004;). On the other hand, important effects of parent-nurse communication in NICU settings have been focused on qualitative studies. Swedish and Australian studies (Lindberg, Axelsson & Öhrling, 2007; Sloan, Rowe & Jones, 2008) suggest the importance of interactions with NICU staff as an information source for the NICU fathers. An American qualitative study (Sisk, Lovelady, Dillard & Gruber, 2006) also revealed that early maternal counselling in a NICU increases the lactation initiation rate. Since this study includes the thematic analysis in addition to the quantitative analyses, it is able to highlight the implicit role of a parent-nurse communication in parental support in these two NICUs.

Differences in the findings regarding parental stress sources between the two NICUs may reflect different underlying infants' care-related philosophy in each NICU. This study has shown that the philosophy of developmental care is embraced by the environments of both NICUs similarly to some extent, however NICU regulations and routine nursing care are

considerably different between the two sites. This suggests that different interpretations of the philosophy and/or the degree of its applicability in the two cultures. In order to investigate environmental influences on parental stress, the Italian study by Trombini, Surcinelli, Alessandroni and Faldella (2008) compared two Italian NICUs characterised by their different philosophies, according to which one provided multi-disciplinary family-centred care and the other limited parental involvement in infants' care. The importance of providing care environments that foster parent-staff dialogue was illustrated, indicating the influence of different NICU policy on parental stress. Varcoe et al. (2004) found that nurses make moral decisions 'in-between' their own values and those of organisations and others in relation to their contexts. The policy differences among NICUs might influence their values in the care of infants and families, resulting in different interpretations of care-related philosophy, such as developmental care, which has been researched worldwide (Als et al., 2004; Lawhon & Hedlund, 2008; Maguire et al., 2008). For example, although the term developmental care is used in a study investigating its efficacy (Maguire et al., 2008), the central role of family in the infants' care, which is fundamental to developmental care, is not fully considered in the study's results (See chap. 2.2, pp. 12-14). This may be due to emphasis on technical intervention in infants' neurobehavioural development which might in turn shape the interpretation of the medical and nursing care in the study site.

The cultural backgrounds of NICUs have been shown to have an enormous impact on study results, and this should be carefully considered when assessing important features of parental support. Parental perceptions of counselling by doctors in NICU settings on the subject of resuscitation, for instance, have been studied cross-culturally, including participants in Hong Kong, Singapore, Kuala Lumpur, Melbourne, San Francisco and Tokyo (Partridge et al., 2005). The authors point out the influence of the degree of medical paternalism in each culture on parental perceptions of doctors' counselling regarding decision-making. For example, of all the groups of parents included in the research (Partridge et al., 2005), the group who presented the lowest percentage of parents who reported having adequate counselling by physicians was one from a NICU in Tokyo city yet they tended to prefer to follow doctors' decisions. Medical paternalism in Japan might explain this contradiction. Nishida and Sakamoto (1992) stated their criteria for medical decision-making regarding neonatal resuscitation used in the Tokyo NICU under study, and the underlying principles:

> The underlying principle applied is 'for the patient, not for the family. … to listen to what they [family] wish us to do for the patient and for them. But most families are not asked to make the final decision' (Nishida & Sakamoto, 1992, p. 404).

The authors also stated that the paternalistic relationship between family and physician in Japan influenced parental decision-making, and that 'it is not fair to place this burden on the family' (Nishida & Sakamoto, 1992, p. 404).

2.4 Summary

As Doane and Varcoe (2005) claim, ethical inquiry is entangled with taken-for-granted ideologies as well as other forms of inquiries. The differences in stress sources between the parents in the two NICUs may be explained in part by the cultural differences that shape parental expectation of NICU medical and nursing care. For instance, due to the dominant ideology of medical paternalism in Japanese NICU settings, the Tokyo parents might not actively seek physical involvement in their baby's care, rather they may expect NICU staff to take charge of their baby's care for them during the early stage of the NICU stay. Therefore, for the Tokyo parents, responding to their parental concerns regarding their infant's condition may be the best way to foster their abilities to cope with their challenges in the NICU. Indeed, this nursing implication has been emphasised in past Western studies (Seideman et al., 1997; Griffin, Wishba & Kavanaugh, 1998; Zelkowitz, Bardin & Papageorgiou, 2007). On the other hand, for the Christchurch parents, as for the past Western-based studies (Griffin et al., 1998; Browne, VandenBerg, Ross & Elmore, 1999), the findings suggest that supporting the parents to take care of their baby with confidence is important. This may reflect the important value of parental autonomy in the NICU among the Christchurch parents. Mifflin (2003) discusses the challenge of balancing the contrasting ideologies of paternalism and autonomy in relation to informed consent in a NICU. Despite the cultural differences, the parental comments make reference to two similar stress-related situations in the two NICUs: ward busy-ness and/or nurses attitudes' that interfered with parents' communication with staff. Both signify situations in which the parents felt they were not being heard by NICU staff – a possible cause of stress in both NICUs. This study has illustrated cultural differences associated with collectivism versus individualism that influence parental perceptions of stress, however balancing parental autonomy and beneficence is a crucial aspect of NICU parental support in both NICUs.

As previous Western studies have demonstrated, valuing parents to take charge of their infants is essential; however, their physical involvement in their infant's care may not always be necessary. In the Christchurch NICU, the philosophy of family-centred care is fundamental to the nursing support and this may well contribute to the lower levels of maternal stress compared to the Tokyo NICU. However, the findings also suggest that the Christchurch parents experienced an increase in stress levels during the last stage of their infant's NICU hospitalisation. This may be in relation to establishing the infant's oral feeding, for the

mothers, and increased responsibilities during the pre-discharge period for the fathers. This suggests that further attention be given to the support offered at this particular time in regard to parental involvement in the infants' care. The findings for the Tokyo NICU might, on the other hand, suggest that the encouragement of parental involvement in the infants' care widely accepted in Western countries may not necessarily be appropriate for Japanese parents in Japanese NICUs. Nurses' assumptions regarding parental willingness to participate in their child's care have been a subject of past studies (Auscott, Donohue, Atkins & Allen, 2002; Coyne, 1995). Parental needs might change over time in different contexts and the needs are diverse. *Listening to* parents will enhance nurses' ability to collaborate with the parents, and this is the way in which nurses can engage families, all of whom have a unique cultural context. In doing so, they can promote families' well-being in the given context at a given moment. In this process of relational inquiry, nurses, by *following the lead of the families*, can reach 'across differences' (Doane & Varcoe, 2005, p.290).

3. *Strengths and Weaknesses of This Study*

This cross-cultural study represents an in-depth exploration of parental experiences with the purpose of identifying nursing roles in parental support in NICU settings. The study has a number of key strengths. The quantitative comparison of the parental NICU experiences in the two cultures has highlighted the relationships between the norms of the NICU care environments and the parental experiences within each NICU. The integration of the underlying philosophy of the relational approach to family nursing into this cultural comparison has enhanced the interpretations of the findings in each NICU cultural context. The inclusion of a qualitative analysis in this study has also enriched the comprehension of the parental experiences in the two NICU settings. Overall, the contextual understanding of parental experiences in each NICU has illuminated *how* nurses engage with families. For example, if this study had focused on only 'quantitative findings', the parental experiences could have been simplified according to race: the Japanese parents were worried about their baby's condition, while the New Zealand parents focused on their parental role. This simple interpretation of the findings would not have led to as fruitful an understanding of parental needs. Cross-cultural quantitative studies may often fall into the trap of stereotyping particular races/ethnic groups, leading the assumption that issues occur among particular people due to their culture, and offering no understanding of the issues beyond the cultural differences. The integrative value of relational inquiry for this study has been supported by a thematic analysis, and has provided an understanding of NICU parental experiences which cannot be generalised from one cultural context to another, and, most importantly, which cannot be generalised even within a particular cultural context.

This study has shown how nurses collaborate with families – by listening to them, reflecting upon their own values and beliefs, and taking actions to support the families in their given contexts at a given moment. Canadian researchers (Bracht, Kandankery, Nodwell & Stade, 2002) described the challenge of developing a cultural competency programme among NICU staff which included the importance of reflecting on one's own values and beliefs so as to establish an effective communication. A possible difficulty in establishing nurses' cultural competency might be in informing nurses *how* to question their own beliefs and values with respect to 'others', that is, *how* to listen to others. In this study, the key nursing role of communicating with families was highlighted in both the Christchurch and Tokyo NICUs – however, this study has demonstrated the ways of communicating with parents that were different between the two NICU cultural contexts. This cross-cultural study has illustrated *how* nurses communicate with the families – this has been the most successful feature of this study.

While bearing mind the strengths of this study, the relatively small sample size used for this research must also be acknowledged. A bigger sample size would have given a more comprehensive account of the parental experiences and greater power for statistical analysis. Moreover, this study has also highlighted the issue of cultural appropriateness of the use of the American-based parental questionnaire, the PSS: NICU, in New Zealand and Japan. In the process of testing internal consistency, the level of internal consistency of the *Sights and Sounds* subscale for the Christchurch mothers was found to be low (0.56). This may be a result of the maternal responses to those situational questions in the PSS: NICU that did not appear to reflect the parental experiences in the current Christchurch NICU. Additionally, the final question, independent of three stress-subscales, was answered by only about 70% of the Christchurch mothers and 60% of the Christchurch fathers though nearly 100% of the Tokyo parents completed this question. The question is not numbered and states: "using the same rating scale, indicate how stressful, in general, the experience of having your baby hospitalized in the NICU has been for you". The reason for the lack of response from the Christchurch parents is unknown.

The differing service delivery and regulations of each NICU may have caused bias in the findings. For example, continuity of nursing staff contact with parents was greater in the Tokyo NICU than the Christchurch NICU. Also, one reason for the Tokyo fathers being less stressed than their Christchurch counterparts might be related to the relatively shorter length of time they spent in the NICU. This difference may in part be related to the differing NICU visiting regulations. The Tokyo fathers would have experienced a greater number of stressful situations if they had spent more time in the NICU than they actually did.

In this study, the Japanese-translated version of the PSS: NICU was originally found to have a good level of internal consistency. However, a particular item in the *Parental Role Alteration* subscale – Not feeding my baby myself – raised the question of content equivalence [9] between the Japanese-translated version and the English version of the questionnaire. Over 80% of the Tokyo fathers (25 fathers out of 30) reported that they did not experience the situation of feeding their baby, while only 50% of their Christchurch counterparts reported the same. At the time of the study, about 60% of the Tokyo infants and 10% of the Christchurch infants were fed orally by bottle, often as a supplement to breastfeeding or tube feeding, suggesting that the fathers of these infants might have had a chance to feed their baby by themselves using a bottle. The large percentage of the Tokyo fathers who reported the experience of feeding their baby to be 'not applicable', undoubtedly indicates their perception of feeding as a gender-specified parental role belonging to the mother. Further, some fathers may have misinterpreted the Japanese word for 'feeding the baby' used in the Japanese-translated version of the questionnaire as meaning 'breastfeeding the baby'. Fortunately, the issue of content equivalence appeared to arise for none of the other questionnaire items. To the author's knowledge, this study is the first English assessment using the PSS: NICU of both maternal and paternal stress amongst Japanese parents in a Japanese NICU, therefore its findings may prove useful for directing further research.

Another possible source of bias in this study is related to differing perceptions of social desirability in each culture, which might derive from differences between the dominant ideologies of individualism (New Zealand) and collectivism (Japan). For example, personal parental comments were collected from about 50% (n=30) of the Christchurch parents and 30% (n=17) of the Tokyo parents. This may reflect differing levels of social acceptability regarding parents critiquing the hospital, as well as differing degrees of medical paternalism between the two countries. It should be acknowledged that these cultural differences might have caused bias in the responses to the main part of the PSS: NICU questionnaire.

Exceptions in the process of data collection may have also caused bias in the results. In the Tokyo NICU, twelve pairs of parents out of 31 pairs self-completed a list of demographic questions (closed questions with some open-ended questions) instead of attending the parental interview, and eight pairs of those parents were given written instruction only for the PSS: NICU (See chap. 4.6, p. 26). This resulted in incomplete demographic data due to missing answers from a couple of participants, however the good level of internal consistency of the

[9] Content equivalence refers to "whether the content domain tapped by each item is equally relevant for the two cultures." (Mallinckrodt & Wang, 2004, p. 368)

PSS: NICU suggests that the missing data were less likely to have a negative influence on the results. Another exception in data collection related to the infants' condition. In the Christchurch NICU, when recruiting participants, the researcher approached parents of infants born at 34 weeks gestation (or late 33 weeks) only 10 days after admission, while in Tokyo the approach was made 14 days after admission (See chap. 4.6. p. 26). This alteration was made according to past data regarding the average length of NICU hospitalisation: shorter in the Christchurch NICU than the Tokyo NICU among the infants born at this particular gestation. Consequently, the length of stay among the infants of this study was relatively shorter in Christchurch than Tokyo, and the difference in data collection may have affected the parental perception of stress-related experiences. Differences in length of stay were one aspect of the culture and context of the two NICUs, and therefore one possible determinant of parental stress, as much as a source of bias.

Importantly, in this study the severity of the infants' condition was not strictly assessed as all the information regarding the infants' condition was collected through the parental interview and the researcher did not have access to the patients' clinical notes. For this reason, the findings may be limited in their illustration of the influence of the infants' condition on the parental stress in the two NICUs. However, the descriptions of the infants' characteristics might have in turn necessarily reflected the parental perceptions of their infant's condition. Therefore, those infant characteristics associated with parental stress sources that were illuminated in this study were from the perspective of the parents, rather than the health professionals.

For the purpose of comparing the findings of this study to those of past studies, the mean scores of each of the stress subscales were calculated among the four groups of parents. These mean scores indicated less than moderate levels of stress, comparable to the findings of other past studies (Carter, Mulder & Darlow, 2007; Dudek-Shriber, 2004; Franck, Cox, Allen & Winter, 2005; Melynyk et al., 2006). This then may indicate that the PSS: NICU successfully captured the parental experiences of the New Zealand and Japanese NICUs regardless of the possible issues discussed above. As this study has focused on describing NICU parental experiences rather than investigating the level of psychological distress of NICU parents, comparisons of the overall stress levels between the two NICUs have not been the subject of close analysis. Similarly, while the Tokyo and Christchurch samples are not necessarily representative of all families in these NICUs, this does not invalidate the findings, given the purpose of the study to explore NICU contextual issues rather than to establish the representativeness of these families' experiences. This study has examined situations in which the majority of the parents experienced moderate or high levels of stress. In this way,

interesting findings related to important aspects of NICU care environments have been illuminated, and have enhanced fruitful understanding of parental experiences in each NICU context, highlighting the best support for NICU parents.

4. *Implications for Nursing Practice and Future Research*

Effective, meaningful communication between parents and staff is the key to providing parental support responsive to parental needs, and thus to reducing or managing parental stress. Indeed, the importance of communication is equally evident in the two NICU settings, highlighting the importance of the nursing role in fostering communication in parental support. However, this study also illustrates the different NICU contexts in which communication is specific to each NICU, demonstrating that *how* nurses communicate with families is not universally the same. The areas of parental support that may require further attention in order to enhance nursing intervention in each NICU are described accordingly as follows.

4.1 Nursing Practice: The Christchurch NICU

Establishing oral feeding: This area of support would be strengthened by increasing staff communication between the large number of nurses so as to provide consistent advice on infants' feeding and care, and to decide upon the degree of support required for individual parents during the establishment of oral feeding.

Infants' care-related decision-making: Decisions regarding day-to-day nursing care increasingly involve the parents in the later stages of NICU hospitalisation. Parents need to be listened to in terms of their infants' care so that they are able to develop their parental skills as their infants' discharge approaches. Parents also value clear, specific medical advice regarding their infants' condition and this will foster their coping ability and thus reduce their stress and anxiety.

4.2 Nursing Practice: The Tokyo NICU

Parental information/involvement in the early stage of hospitalisation: Parents need to be informed/listened to regarding their infants' condition and everyday progress, in particular while their infants are in intensive care – requiring an incubator and/or tube feeding – during which time parents feel they cannot do anything for their baby. Parental involvement during this early stage of hospitalisation can be encouraged and increased according to individuals' needs by providing adequate parental guidance.

Influence of visiting regulations on parental stress and anxiety: Nurses' awareness of this influence is important. Parents as well as nurses may not be aware that they are constrained by the regulations which limit visiting time that they have become so familiar with in their NICU context. However, an awareness of the regulations as drivers of parental stress will motivate nurses to listen to parents actively, leading to reduced stress regardless of the limited time allowed for both parents and nurses to interact.

Importing Western-based NICU intervention: As in the Christchurch NICU, the philosophy of developmental care has been integrated into the infants' care in the Tokyo NICU, in conjunction with a focus on fostering their neurobehavioural development. However, in terms of family-centred care delivery, the philosophy does not appear to be fully reflected in NICU regulations/routine nursing care. This may be due in part to the dominant ideology of medical paternalism in the NICU, indicating difficulties in applying Western-based intervention to Japanese parents. Nevertheless, when importing Western philosophy into the NICU care, the contextual applicability to the workforce environment should also be considered. For example, the nurse-patient ratio, number of nursing staff, and the staff's average length of NICU experience are considerably different from the Christchurch NICU where the BFHI (See chap. 5.5, pp.33-34) is central to their care delivery. Importing Western-based nursing intervention will be successful when these contextual aspects are fully addressed.

4.3 Future Research

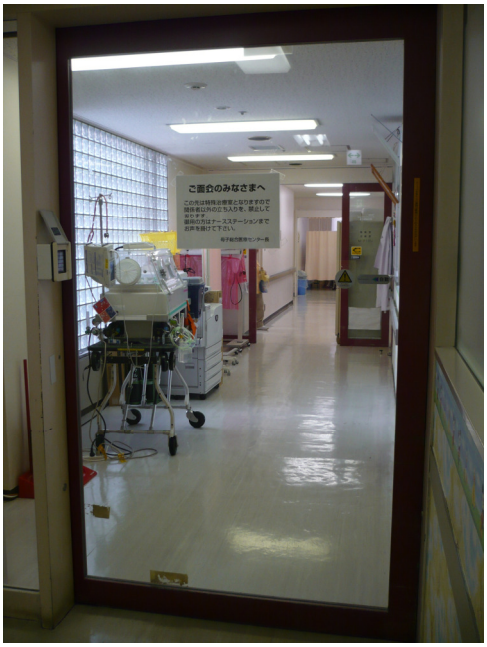
This study has implications for future cross-cultural research into parental support of infants in a NICU. These implications include:

- The desirability of further similar research, with a larger sample, to establish or refute the findings from this study
- Further development and validation of the PSS: NICU, or other cultural equivalent psychometric measures for assessing parental stress
- Investigation of cultural differences in nursing perspectives towards care delivery – for instance, attitudes towards nursing decision-making regarding the degree of parental care involvement, and the amount of day-to-day information given to parents regarding the infants' condition and their required medical/nursing care
- Investigation of cultural differences in the relationship between the amount and/or content of parent-nurse communication, and parental stress
- Investigation of cultural differences in sources of parental stress and anxiety, and parental coping strategies following NICU discharge

Conclusion

This study has highlighted the influence of the norms and cultures of the Christchurch and the Tokyo NICUs in relation to NICU regulations and nursing care, as these impacts on parental stress-related experiences, and the importance of reflecting upon these norms to critique those professional beliefs which may hamper parental coping abilities. The areas of parental support needing attention were different between the two NICUs, however this research has made evident that meaningful communication is essential to fostering nursing support cross-culturally. Indeed, the parental response to the infants' NICU hospitalisation varies from one culture to another as well as within a culture. One way to reach across these differences is to listen to parents, and this, it is clear, is crucial to the role of nurses in NICU settings.

Figure 5: The Tokyo NICU



The Corridors – parents walk along these to see their babies everyday.

Figure 6: The Christchurch NICU

The photos reproduced by courtesy of each NICU

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Appendices

Required information from the two Neonatal Intensive Care Units:

1. Medical protocols and hospital guidelines:
   - Medical conditions/ criteria for admitting to NICU
   - transferring to different levels of care
   - Involvement of Multi – Disciplinary – Team(MDT)
   - Visiting rules
   - Post-discharge support (where is the family referred to ?)

2. Job descriptions of nursing staff:
   - Employed numbers of nursing staff
   - Employment status
   - Working conditions (shifts/ working hours)
   - Patient–nurse ratio

3. The roles of nurses:
   - Guidelines for routine nursing care for the infants from birth to discharge
   - Nursing model used
   - Continuity in allocating the same patient to the same nurse
   - Daily work- descriptions
   - Discharge planning
   - Involvement in MDT

4. General characteristic of nurses in the two units:
   - Average years of NICU experience
   - Average age
   - Sex

5. The roles of family
   - Family involvement in care of their infant in the units from birth to discharge
   - Utilization of social support (from an organization both inside and outside of the hospital)
   - Involvement in decision-making and discharge planning

6. NICU physical environment:
   - Lighting and sounds
   - Size of rooms

Family Background Interview (approx. 30 mins)

Instruction: You do not have to answer all of the questions if you do not wish to.

Interviewing: mother / father

A. About a baby:

1) Boy / Girl

- Does s/he have a sibling(s)? Yes/ No
- If yes, how many sisters and brothers dose s/he have? How old are they?

Sisters	Brothers

2) Date of birth

3) Type of delivery: Vaginal / Caesarean / Forceps

4) Birth weight

5) Gestation at birth / Expected delivery date

6) Gestational age

7) Length of stay in NICU (at the time of interviewing)

8) Did/ are your baby need/ going to need surgery? Yes/ No

- If yes, what kind of surgery?

9) Did/does s/he need oxygen therapy? Yes/ No

- If yes, how long?

10) Feed: Breast feed/ Tube feed/ Bottle feed (Expressed breast milk/ Formula/ Special formula)

11) Did s/he need tube feeding? Yes/ No

- If yes, how long?

B. About family members:

1) Age of mother ( ), and father ( )

2) Ethnicity:

- Mother:
- Father:

3) Marital status: Defacto / legally married / civil union

- Are you living with a partner at the present time? Yes/ No

4) Who is currently living with you at home apart from new baby? How many? ( )

Relationship/		Relationship/	

- Is the baby going to live with them? Yes/ No
- If not, who is going to live with the baby?

5) Living area:

- Which area/ suburb do you live?
- How long does it take to get to the hospital normally?
- How do you get to the hospital normally?

6) Parental qualification:

	Mother	Father
School qualification		
Professional qualification		

- School qualification: 1= secondary school, 2=high school, 3=post-school certificate,4= diploma, 4= degree, 5=university degree

7) Employment status:

	Mother	Father
Occupation		
Working Hours		

- For mother: If not working currently (except on maternal/ paternal leave), were you working before you had your baby? Yes/ No
- If yes, what did you do?

C. About support

1) Is there any support person/ people who help you and your partner with house work or other commitments? Yes/ No

- If yes, what do they help you with? House work? Shopping? Childcare? Transport? Work (self-employed?)
- Who are they? Your (or your partner's) parents? Siblings? Other relatives? Friends?

2) Did you attend antenatal classes? Yes/ No

3) Family visiting to NICU:

	Mother	Father	( )	( )	( )
Frequency of visiting					
Length of stay on per visit					
Any particular time of the day for visiting Time					

Ethnicity

1	NZ Maori
2	NZ European
3	Other European
4	Pacific Islander
5	Asian
6	Others (specify)

Educational Qualifications

1	Secondary School Qualification
2	University Entrance
3	Trade/ Professional Qualification(s)
4	University Degree(s) or Diploma(s)

お子さん、ご家族についてお伺いさせていただいております。　以下、できる範囲で結構ですので、各質問にお答えください。　選択肢がある場合は、当てはまる方に　マル○　をおつけください。

✧　この質問用紙に記入をしてくださっているのは：　お母様　/　お父様　/　ご両親

お子さんについて

- 性別：　男児　/　女児
- お誕生日：
- 出生時の体重：
- 出生時の週数：
- 分娩様式：　普通分娩　/　帝王切開
- 出生場所：　当院　/　他院
- お子さんの現在の週数（この質問用紙に記入されている日）：

お子さんはこれまでに手術など、外科的な治療を必要とされましたか？

いいえ　/　はい - どのような手術でしたか：

お子さんは酸素療法を必要とされましたか？

いいえ　/　はい - 出生時より今現在、酸素療法中である　/　以前必要であった：どのくらいの期間必要でしたか？

お子さんの栄養摂取について、以下、該当するものに　マル○　をお付けください。

お子さんのミルクは：　搾乳　/　人工乳　/　混合（搾乳と人工乳）

お鼻のチューブを使ってミルクを飲んでいる　/

お鼻のチューブと哺乳瓶の両方を使ってミルクを飲んでいる

ご家族について

- 年齢：　お父様（　　）　お母様（　　）
- 国籍：　お父様（　　）　お母様（　　）
- 最終学歴（例：高卒　大卒）：　お父様（　　）　お母様（　　）
- 専門・職業資格（例：調理師　教員）：お父様（　　）　お母様（　　）
- 職業：　お父様：

　　- 通常の就業時間（例：月－金曜の９時から５時）：

　　お母様：専業主婦　産休中　今回のご妊娠・ご出産を契機にご退職 - 以前のご職業：

- お住まいの地区：　都内　/ その他
- ご自宅から当院までのおおよその所要時間と通常お使いになる交通手段（例：車で１時間）：

現在、ご自宅に一緒に住んでいらっしゃるのはどなたですか？

お子さんは退院後、今現在お住まいのご自宅に帰られますか？
　はい　/ いいえ - どちらで退院後過ごされる予定ですか（例：里帰り）

サポートについて

今現在、生活面で何か手伝ってくださる方はいらっしゃいますか？
　いいえ　/ はい - どのようなことでしょうか（例：買い物、家事、送り迎え）

- どなたが主に手伝ってくださいますか(例：お母様の実母)

両親学級へのご参加について、参加されたことのある場合、以下に　マル○　をお付けください。

母親学級　/ 父親学級　/ 両親学級

ご面会について

- 面会頻度（例：週に３回）：　お父様（　　）　お母様（　　）
- 一回の面会時間（例：１時間）：　お父様（　　）　お母様（　　）
- ご両親以外のご面会（窓ごし面会含む）：　なし　/ あり - どなたがいらっしゃいましたか？　また、何回くらいお見えになりましたか？

当施設では面会時間の制限をさせていただいておりますが、こちらの面会時間外で、ご両親のご都合のよい時間帯はありますか？　いいえ　/ はい - 何時くらいでしょうか？

ご協力、大変、ありがとうございました。

お子さん、ご家族についてお伺いさせていただいております。　以下、できる範囲で結構ですので、各質問にお答えください。　選択肢がある場合は、当てはまる方に　マル○　をおつけください。　　＊　ご記入日：　　年　　月　　日

お子さんについて

- 性別：　男児　/　女児
- お誕生日：
- 出生時の体重：
- 出生時の週数：
- 分娩様式：　普通分娩　/　帝王切開　/　かんし分娩
- 出生場所：　当院　/　他院
- お子さんの現在の週数（この質問用紙に記入されている日）：

お子さんはこれまでに手術など、外科的な治療を必要とされましたか？

いいえ　/　はい - どのような手術でしたか：

お子さんは酸素療法を必要とされましたか？

いいえ　/　はい - 出生時より今現在、酸素療法中である　/　以前必要であった：どのくらいの期間必要でしたか？

お子さんの栄養摂取について、以下、該当するものに　マル○　をお付けください。

- お子さんのミルクは：　搾乳　/　人工乳　/　混合（搾乳と人工乳）
- お鼻のチューブを使ってミルクを飲んでいる　/　お鼻のチューブと哺乳瓶の両方を使ってミルクを飲んでいる　/　哺乳瓶を使ってミルクを飲んでいる　/　直接母乳している　/　直接母乳と哺乳瓶の両方
- 現在、哺乳瓶を使用、もしくは直接母乳をしているお子さんについてお伺いします。今までにお口・お鼻のチューブを使ってミルクを飲んでいたことがありましたか？
  いいえ　/　はい - どのくらいの期間、チューブを使っていましたか？

ご家族について

- 年齢：　お父様（　　才）　お母様（　　才）
  ご兄弟　なし/ 姉（　　才）/ 兄（　　才）
- 国籍：　お父様（　　）　お母様（　　）
- 最終学歴（例：高卒　大卒）：　お父様（　　）　お母様（　　）
- 専門・職業資格（例：調理師　教員）：お父様（　　）　お母様（　　）
- ご職業について：

お父様:会社員/　自営/　公務員/　会社経営/　その他　（　　）
- 勤務形態（例：週５日勤務）:
- 通常の就業時間（残業含）(例：１日１０時間):

お母様:専業主婦/　産休中(会社員/　自営/　公務員/　その他　　)
/今回のご妊娠・ご出産を契機にご退職 - 以前のご職業：

- お住まいの地区：　都内　/ その他
- ご自宅から当院までのおおよその所要時間：
  - 通常お使いになる交通手段：

現在、ご自宅に一緒に住んでいらっしゃるのはどなたですか？
- お母様がお里帰り中の場合、お父様、赤ちゃんのご兄弟（当てはまる場合）はどなたとお住まいですか？

お子さんは退院後、今現在お住まいのご自宅に帰られますか？
はい　/ いいえ - どちらで退院後過ごされる予定ですか（例：里帰り）

サポートについて

今現在、生活面で何か手伝ってくださる方はいらっしゃいますか？
いいえ　/ はい - どのようなことでしょうか（買い物/ 家事/ 送り迎え/子供の世話）

- どなたが主に手伝ってくださいますか(例：お母様の実母)

両親学級へのご参加について、参加されたことのある場合、以下に　マル○　をお付けください。　　母親学級　/ 父親学級　/ 両親学級

ご面会について

- 面会頻度(例:週に３回):　お父様(　　)　お母様(　　)
- 一回の面会時間(例:１時間):　お父様(　　)　お母様(　　)
- ご両親以外のご面会（窓ごし面会含む):　なし　/ あり - どなたがいらっしゃいましたか？　また、何回くらいお見えになりましたか？

当施設では面会時間の制限をさせていただいておりますが、こちらの面会時間外で、ご両親のご都合のよい時間帯はありますか？
いいえ　/ はい - 何時くらいでしょうか？

ご協力、大変、ありがとうございました。

Appendix F:

Parental Stress Scale: Neonatal Intensive Care Unit (PPS: NICU)

(Miles, 2002)

Note: A title of this study was inserted into an original version of the PSS: NICU (2002; available online – see References) as per the Upper South A Regional Ethics Committee (New Zealand).

PARENTAL STRESS SCALE: NEONATAL INTENSIVE CARE UNIT

Nurses and others who work in neonatal intensive care units are interested in how the experience of having a sick baby hospitalized in the neonatal intensive care unit (NICU) affects parents. We would like to know what aspects of your experience as a parent are stressful to you. **By stressful, we mean that the experience has caused you to feel anxious, upset, or tense.**

This questionnaire lists various experiences parents have reported as stressful. Please indicate how stressful each item listed below has been for you using the following scale:

1 = Not at all stressful: the experience did not cause you to feel upset, tense, or anxious
2 = A little stressful
3 = Moderately stressful
4 = Very stressful
5 = Extremely stressful: the experience upset you and caused a lot of anxiety or tension

If you did not have the experience, indicate this by circling N/A meaning that you have "not experienced" this aspect of the NICU.

Now let's take an item for an ***example***: The bright lights in the NICU.

If for example you feel that the bright lights in the neonatal intensive care unit were extremely stressful to you, you would circle the number 5 below:

NA 1 2 3 4 **5**

If you feel that the lights were not stressful at all, you would circle the number 1 below:

NA **1** 2 3 4 5

If the bright lights were not on when you visited (not likely), you would circle NA indicating "Not Applicable" below:

NA 1 2 3 4 5

Now begin

Below is a list of the various **SIGHTS AND SOUNDS** commonly experienced in an NICU. We are interested in knowing about your view of how stressful these **SIGHTS AND SOUNDS** are for you. Circle the number that best represents your level of stress.

1.	The presence of monitors and equipment	NA 1 2 3 4 5
2.	The constant noises of monitors and equipment	NA 1 2 3 4 5
3.	The sudden noises of monitor alarms	NA 1 2 3 4 5
4.	The other sick babies in the room	NA 1 2 3 4 5
5.	The large number of people working in the unit	NA 1 2 3 4 5
6.	Having a machine (respirator) breathe for my baby	NA 1 2 3 4 5

Below is a list of items that might describe the way your **BABY LOOKS AND BEHAVES** while you are visiting in the NICU as well as some of the **TREATMENTS** that you have seen done to the baby. Not all babies have these experiences or look this way, so circle the NA, if you have not experienced or seen the listed item. If the item reflects something that you have experienced, then indicate how much the experience was stressful or upsetting to you by circling the appropriate number.

1.	Tubes and equipment on or near my baby	NA 1 2 3 4 5
2.	Bruises, cuts or incisions on my baby	NA 1 2 3 4 5
3.	The unusual color of my baby (for example looking pale or yellow jaundiced)	NA 1 2 3 4 5
4.	My baby's unusual or abnormal breathing patterns	NA 1 2 3 4 5
5.	The small size of my baby	NA 1 2 3 4 5
6.	The wrinkled appearance of my baby	NA 1 2 3 4 5
7.	Seeing needles and tubes put in my baby	NA 1 2 3 4 5
8.	My baby being fed by an intravenous line or tube	NA 1 2 3 4 5
9.	When my baby seemed to be in pain	NA 1 2 3 4 5
10.	When my baby looked sad	NA 1 2 3 4 5
11.	The limp and weak appearance of my baby	NA 1 2 3 4 5
12.	Jerky or restless movements of my baby	NA 1 2 3 4 5
13.	My baby not being able to cry like other babies	NA 1 2 3 4 5
14	My baby crying for long periods	NA 1 2 3 4 5
15	When my baby looked afraid	NA 1 2 3 4 5
16	Seeing my baby suddenly change color (for example, becoming pale or blue)	NA 1 2 3 4 5
17	Seeing my baby stop breathing	NA 1 2 3 4 5

The last area we want to ask you about is how you feel about your own **RELATIONSHIP** with the baby and your **PARENTAL ROLE.** If you have experienced the following situations or feelings, indicate how stressful you have been by them by circling the appropriate number. Again, circle NA if you did not experience the item.

1.	Being separated from my baby	NA 1 2 3 4 5
2.	Not feeding my baby myself	NA 1 2 3 4 5
3.	Not being able to care for my baby myself (for example, diapering, bathing)	NA 1 2 3 4 5
4.	Not being able to hold my baby when I want	NA 1 2 3 4 5
5.	Feeling helpless and unable to protect my baby from pain and painful procedures	NA 1 2 3 4 5
6.	Feeling helpless about how to help my baby during this time	NA 1 2 3 4 5
7.	Not having time to be alone with my baby	NA 1 2 3 4 5
8.	Sometimes forgetting what my baby looks like	NA 1 2 3 4 5
9.	Not being able to share my baby with other family members	NA 1 2 3 4 5
10	Being afraid of touching or holding my baby	NA 1 2 3 4 5
11	Feeling staff is closer to my baby than I am	NA 1 2 3 4 5

Using the same rating scale, indicate how stressful in general, the experience of having your baby hospitalized in the NICU has been for you:

1 = Not at all stressful: the NICU experience did not cause me to feel upset, tense, or anxious
2 = A little stressful
3 = Moderately stressful
4 = Very stressful
5 = Extremely stressful: the NICU experience upset me and caused a lot of anxiety or tension

Thank you for your help. Now, was there anything else that was stressful for you during the time that your baby has been in the neonatal intensive care unit? Please discuss below:

✳ Please feel free to use the space below to share any experiences that have been stressful for you during your child's stay in NICU. This information is for the use of my study, but your feedback will be passed on to my supervisors.

親のストレススケール：新生児集中治療室（ＮＩＣＵ）

新生児集中治療室（NICU）の看護師など医療従事者は、お子さんが NICU に入院していることがご両親にとってどのように影響を与えるかということについて調査し今後に役立てていきたいと考えております。そこで、親としてのどのような体験がストレスになるかということについてお伺いしたいと思っております。ここでいう**ストレスとは、それらの体験によりあなたが不安になったり、動揺したり、または神経や感情が張り詰めたりした状態のことを意味します。**

このアンケートはストレスを感じたとするご両親の色々な経験報告にもとづき作成されています。あなたがどれくらいストレスを感じたか、次のページ以降のアンケートの質問に対しそれぞれ下の項目の中で適切なものを選んでください。

1＝まったくストレスを感じない：その体験により、動揺することもなく、神経や感情が張り詰めたり、または不安になったりもしなかった。
2＝少しストレスを感じる
3＝ある程度ストレスを感じる
4＝とてもストレスを感じる
5＝かなりストレスを感じる：その体験は自分をとても動揺させ、かなりの不安または神経や感情の緊張をもたらした。

＊もしあなたが　NICU で実際に体験されなかった場合は**ＮＡ**を丸で囲んでください。ＮＡ（Not Applicable）は‘体験しなかった’ことを意味します。

１つ、**例**を挙げてみましょう。　新生児集中治療室（NICU）の明るいライトについて：
NICU　の明るいライトでかなりストレスを感じたとすれば下の５に丸をつけてください。

ＮＡ　１　２　３　４　⑤

NICU のライトがまったくストレスと感じなかったのであれば下の１に丸をつけてください。

ＮＡ　①　２　３　４　５

NICU のライトがあなたの面会時間点灯していなかった場合（ほとんどありえませんが）は下のＮＡ　に丸をつけてください。

ⓃⒶ　１　２　３　４　５

では、ここから質問にはいります。

１．次の項目は、NICU　でよくみられる光景と騒音について挙げられています。あなたがこれらの項目に対してどのようにストレスを感じたか､あなたのストレスレベルを示す適切なものに丸を付けてください。

１）　モニター（監視装置）や医療器具が置いてあること　ＮＡ　１　２　３　４　５

２）　継続的なモニターや医療器具の音　ＮＡ　１　２　３　４　５

３）　モニターアラームの突然の音　ＮＡ　１　２　３　４　５

４）　同室している他の子ども　ＮＡ　１　２　３　４　５

５）　NICU 内の大勢のスタッフ　ＮＡ　１　２　３　４　５

６）　子どもが人工呼吸器をつけていること　ＮＡ　１　２　３　４　５

２．次の項目は、NICU での面会中のあなたのお子さんの様子、及び、あなたが目にされたことがあると思われる治療処置について挙げられています｡あなたが体験された中で当てはまるものがあれば、どれだけストレスを感じたか、適切なものに丸を付けてください。あなたの体験上当てはまらない場合は　ＮＡ　に丸を付けてください。

１）医療チューブ（管）や医療機器が子どもに付いている、もしくはすぐ周りにある
ＮＡ　１　２　３　４　５

２）子どもの体に青あざ、切り傷、外科的治療の痕がある　ＮＡ　１　２　３　４　５

３）子どもの皮膚の色が悪い（例：青白く見える、または黄疸色）
ＮＡ　１　２　３　４　５

４）子どもの正常ではない、もしくは苦しそうな呼吸の様子
ＮＡ　１　２　３　４　５

５）子どもの体が小さい　ＮＡ　１　２　３　４　５

6）子どもに肌のはりがない　ＮＡ　１　２　３　４　５

7）針や管の挿入されるところを見る　ＮＡ　１　２　３　４　５

8）点滴または管で子どもに栄養が与えられている　ＮＡ　１　２　３　４　５

9）子どもが痛がっているような様子　ＮＡ　１　２　３　４　５

１０）　子どもが悲しそうに見える様子　ＮＡ　１　２　３　４　５

１１）　子どものぐったりとして弱々しい様子　ＮＡ　１　２　３　４　５

１２）　子どもの引きつけのような、または落ち着かない動き
ＮＡ　１　２　３　４　５

１３）　子どもが他の子のように声を上げて泣くことができない
ＮＡ　１　２　３　４　５

１４）　子どもが長時間泣き止まない　ＮＡ　１　２　３　４　５

１５）　子どもに怖がっている様子が伺える　ＮＡ　１　２　３　４　５

１６）　子どもの皮膚の色が突然悪くなるのを見る（例：蒼(青)くなる）
ＮＡ　１　２　３　４　５

１７）　子どもが無呼吸になっているのを見る　ＮＡ　１　２　３　４　５

３．次の項目は、あなたとお子さんとの関係又はあなたの親としての役割についての問いです。もしあなたが次の状況を経験されたか、または感じた事があれば、どれくらいストレスを感じられたか適切なものに丸を付けてください。前頁と同じく、経験がない場合は　ＮＡ　に丸を付けてください。

1）子どもから離されている　ＮＡ　１　２　３　４　５

2）自分で子どもに授乳できない　ＮＡ　１　２　３　４　５

3）入院によって自分で子どもの世話をすることが出来ない(おむつ交換や沐浴･体拭きなど)
ＮＡ　１　２　３　４　５

4）自分が抱きたいときに子どもを抱けない　ＮＡ　１　２　３　４　５

5）子どもが痛がっていたり痛みを伴う医療処置をされたりしている時に守る事ができない、または無力感を感じる　ＮＡ　１　２　３　４　５

6）今、子どもに何をしてあげたらいいのか分からず、どうしようもない思いを感じる
ＮＡ　１　２　３　４　５

7）子どもと自分だけの時間がない　ＮＡ　１　２　３　４　５

8）時々子どもがどんな姿か思い出せない時がある　ＮＡ　１　２　３　４　５

9）子どもと共に家族みんなで過ごすことが出来ない　ＮＡ　１　２　３　４　５

１０） 子どもを触ったり、抱っこしたりすることを戸惑ってしまう
ＮＡ　１　２　３　４　５

１１） NICU のスタッフが、自分よりも子どもと近い関係にあるように感じる
ＮＡ　１　２　３　４　５

４．　最後に、お子さんが　NICU に入院したという経験が全体的にどれくらいストレスになっているか選んでください。

1＝まったくストレスを感じない：この経験によって動揺することもなく、また神経や感情が張り詰めたり、もしくは不安になったりもしなかった。
２＝少しストレスを感じる
３＝ある程度、ストレスを感じる
４＝とてもストレスを感じる
５＝かなりストレスを感じる：この経験は自分をとても動揺させ、かなりの不安または神経や感情の緊張をもたらした。

ご協力どうも有難うございました。

上記のアンケート内容の他にお子さんがＮＩＣＵに入院している間で、何かストレスに感じた事またはご意見があればこちらにご記入下さい。

このアンケートは以下の研究者によって作成されました。

c Margaret S. Miles, RN, PhD 2001, Carrington Hall, CB 7460, School of Nursing University of North Carolina, Chapel Hill, NC 27599-7460

Health Sciences Centre

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Email: healthsciences@canterbury.ac.nz

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CHRISTCHURCH NEW ZEALAND

Information Sheet for parents on the study of:

Nursing Roles in Parental Support: A cross-cultural comparison between Neonatal Intensive Care Units in New Zealand and Japan

Dear Parents, 13 / 2 / 2008

Thank you very much for your time in reading this information sheet. You are invited to take part in a Master's dissertation research study. This study aims to analyse the nursing roles which support parents whose child(ren) is hospitalised in Neonatal Intensive Care Units (NICUs) in two Western and Eastern countries. The research will take place in a NICU in both Christchurch and Tokyo (Japan).

This information sheet will explain why this study is being done, and what will be required of participants as well as how this study will be carried out. This information will help you to decide whether you wish to take part in this study. You might ask your friends, whanau/ family members or support people to help you make up your mind.

You will be asked whether you would like to take part or if you would like to have more time to think about participation within 3 or 4 days after you have received this information sheet.

Why is this study being done?

A child's hospitalisation in a Neonatal Intensive Care Unit (NICU) is a very stressful experience. This experience can cause parents to feel anxious, upset or tense, and these feelings may be the same across different cultures. Nursing support can help reduce parental stress/ anxiety and can help parents'/ families' ability to cope with their unfamiliar/ unexpected experiences in NICU settings. It is crucial that nurses understand how they can support parents so that the parents can help their child(ren) and enhance their child(ren)'s development during/ after the NICU admission. In order to provide nursing support which responds to parents' needs, hence reducing their stress/ anxiety, it is important for nurses to know what makes parents feel stressed, anxious or upset during their child(ren)'s NICU hospitalisation. The sources of stressors in parents of child(ren) in NICU settings may be different from culture to culture. Cultural differences may influence the medical systems/ environment in Western and Eastern countries and this may affect parental roles as well as nursing roles in NICU settings. This study will look at parental stress and nursing support, with consideration given to the cultural differences between New Zealand and Japan.

What is the aims of this study?

- To identify the sources of parental stress that may be particularly responsible for increasing their stress in the NICU.
- To analyse the relationship between the particular sources of parental stress and

nursing roles which may reduce parental stress.

- To analyse the nursing roles that support parents to cope with the particular areas of parental stress in both countries in order to analyse their differences and similarities.

Who are invited to take part in this study?

Parents whose child(ren) is hospitalised in one of the two NICU settings in Christchurch and Tokyo during the period between March 2008 and June 2008 for Christchurch participants, and November 2007 and January 2008 for Tokyo participants. This study requires approximately 30 pairs of parents in each country.

What are the roles of participants?

1. You will be asked for one interview by a principal researcher (Emiko Ichijima). This interview may take approximately 30 minutes. During the interview, an explanation of the questionnaire will be given and general questions will be asked relating to the family background. The researcher will answer any questions that you may have.

- ***Where will the interview be held?***
  In a quiet room within the NICU where privacy will be ensured.
- ***When?***
  A suitable time will be individually arranged with you.
- ***Who will be interviewed?***
  It is your choice to decide who is going to attend the interview. For example, both parents of the child(ren) can attend together, a single parent only can attend, or attendance can be with a support person/ whanau.

2. A parental questionnaire will be given to you. This questionnaire can be completed in your own time. This may take approximately 30 minutes.

- ***About the questionnaire:***
  The established questionnaire **Parental Stress Scale: Neonatal Intensive Care Unit (PSS: NICU)** (Miles, 2002) will be used in this study. This assesses three specific sources of stress: *sights and sounds of the NICU, infant behaviour and appearance, and parental role alteration.* Each item is rated on a scale of 1 to 5.
- ***Who will fill in the questionnaire?***
  Both parents will be asked to individually fill in the questionnaire. However, it is totally your choice to decide whether you wish to complete the questionnaire. You do not have to answer all of the questions if you do not wish to.

What are the benefits or risks of this study?

As a participant you may benefit from feedback regarding the collected data from the questionnaire. The feedback will be available to you on your request. In addition, a brief summary of the study results will be posted to you when the project is completed if you check this option on the consent form. The results will identify the nature of stress experienced by parents whose child(ren) require NICU hospitalisation. The study will hopefully assist nurses to develop strategies to help parents manage their stress in NICU.

It is expected that there will be no risks associated with your participation, however, if the completion of the survey raises issues or anxieties for you which you would like to discuss please contact the study supervisors or myself.

With your permission, data from this study may be used in future related studies, which have been given approval from a Health & Disability Ethics Committee.

Will any payments be made to participants?

No. There will be no payment made from participating in this study.

Who can support the participants if there are any concerns?

Nursing staff will be asked for support where appropriate during/ after the participation.

The principal researcher, Emiko Ichijima (Emi) can be contacted if there are any concerns/ questions. If needed, the supervisors of this research study can also be contacted (please refer the contact details below).

How much information of the participants will the researcher access?

The principal researcher will have information only from the interview and the questionnaire. She will not access any clinical records of the child(ren) of the participants.

How will the confidentiality be kept?

All information will be confidential and participants' details will not be identified in this study. The collected questionnaire and general questions' sheet will be stored within the principle researcher's locked box. The data will be stored on the principle researcher's password-protected personal computer. The data will be stored securely for 10 years at the Health Sciences Centre, University of Canterbury.

Participation is totally voluntary. At any stage, the participants can ask any questions, withdraw their consent or refuse any part of the study.

Who is supervising this study?

This study is being undertaken at the University of Canterbury.
Supervisors:

Dr Ray Kirk, Acting Director, Health Sciences Centre
Professor Andrew Hornblow, Health Sciences Centre
Telephone: 03 366 7001 ext 8691 (Health Science Centre)
Dr Nicola Austin, Clinical Director, Neonatal Intensive Care Unit
Jan McKenzie, Discharge Facilitator/ Neonatal Outreach Nurse Coordinator, Neonatal Intensive Care Unit, Christchurch Women's Hospital

Thank you very much for your time in considering participation in this study. Please do not hesitate to contact either the principal researcher or her supervisors for further information.

Principal Researcher:

Emiko Ichijima – Email: eic14.student@canterbury.ac.nz
Telephone: 03 364 7628 (Health Science Centre)

This study has been given approval by the Upper South A Regional Ethics Committee. If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone (NZ wide): 0800 555 050
Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)
Email (NZ wide): advocacy@hdc.org.nz

Appendix I: Parental Information Sheet (JP)

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面接およびアンケートへのご協力のお願い

２００７年１１月

保護者の皆様へ

研究者： 私、一島栄美子は、東京女子医科大学病院の新生児集中治療室（ＮＩＣＵ）・病児室に看護師として９年前に所属していた者です。 その後、 ニュージーランドへ渡り、同国の看護師資格を取得し、現在、公立クライストチャーチ病院の小児科病棟で働いております。 数年前より、ニュージーランドのカンタベリー大学大学院修士課程の保健科学研究科で NICU を卒業したお子さんとそのご家族への NICU 入院中及び退院後の看護・教育面でのサポートケアについて学んでおります。 このたび、本施設の NICU で、大学院修士課程の卒業研究に取り組ませていただいております。 どうぞ、よろしくお願いいたします。

私は現在下記のテーマで研究に取り組んでおります。 大変恐縮ではございますが、面接及びアンケートのご協力についてご検討くださいますようお願い申し上げます。

研究題目：

両親へのサポートのなかでの看護師の役割： ニュージーランドと日本の新生児集中治療室（NICU）における両親のストレスの要因、及び看護師の役割についての文化的比較考察

研究背景・目的：

お子さんの NICU への入院は、ご両親・ご家族にとって言葉では表せないくらい、とても心配・不安であると思います。また、NICU に入院しているお子さんにとって、ご両親・ご家族は最大なサポートとなることは言うまでもありません。ご両親・ご家族がお子さんをサポートしやすいよう、看護師が担う役割について考えることは 医療・看護を提供する上で重要なことだと思います。NICU という慣れない環境のなかでのご両親の不安・ストレスをどうすれば軽減することができるのか、お子さんと同様にご両親を中心としたサポートのあり方について看護師として理解を深めたいと考えております。それには、ご両親が実際に NICU で、どういう部分にストレスを多く感じているのかを知ることが私たち医療従事者にとっての第一歩ではないかと思います。例えば、西洋諸国での研究では出生直後からのご両親のお子さんへの日常ケアへの参加により、ご両親のストレスが軽減され、退院後の子育ての助けになることなどが報告されています。ただ、このような研究は西洋諸国からの報告が主だっています。そのため、今回の研究では、NICU を取り巻く医療システム及びその環境においての文化的な違いを踏まえ、面接・アンケートを通して、ご両親・ご家族へのサポートのあり方、そして看護師の役割について改めて理解を深めることを目的としています。

研究方法：

- 対象施設：日本(東京女子医科大学病院)・ニュージーランド(公立クライストチャーチウーマンズ病院)の各 NICU 施設
- 対象者：各施設にて３０組のご両親
- ご両親への面接及びアンケート：ご協力を承諾してくださったご両親を対象に面接及びアンケートを実施させていただきます。

１．**面接について：**

３０分ほど、お時間を頂き、院内(プライバシーが厳守できる場所)にて、入院中のお子さん・ご両親・ご家族のことついてお話しを伺わせて頂きます。この面接時に、アンケートをお渡しし、それについての説明をさせて頂きます。

２．**アンケートについて：**

英文アンケートを翻訳したものを用います。これは、

① お子さんの NICU 入院によりご両親にとってどういったことがストレスになるかについて知るためのアンケートです。
② 35 の短い質問項目で成り立っています。
③ ５段階評価（ストレスの度合いを１から５の数字を用いて表します）にて各質問に回答していただきます。

Appendix I: Parental Information Sheet (JP)

- アンケートは無記名で行います。お持ち帰り頂き、後日回収いたします。

倫理的配慮について：

- 面接・アンケートへのご協力について、同意書を作成し、ご両親から承諾を頂いた上で面接を行い、アンケートを配布します。
- それぞれの入院児の身体的・社会的情報に関しては原則的にご両親から伺った情報のみ使用し、カルテその他の医療情報には私個人が関与することはありません。
- 集計過程・結果において、個人が特定されることはありません。
- 面接及びアンケートへのご協力は、その途中であっても中止はいつでもできます。
- 個人情報、データは鍵のかかる場所および研究者専用パスワードで保護されたパーソナルコンピューター内に保存致します。また、それらの情報はカンタベリー大学大学院保健科学研究科に７年間保管された後、破棄致します。

研究結果について：

この研究をまとめた文書に関しては完成時にご希望の方にお渡しいたします。

この研究にご協力を頂いたことが、今後、ご両親へのサポートのあり方について看護師の理解を深めるひとつの機会となることを心から願っております。

研究指導者：

Dr. Ray Kirk、ニュージーランド国立カンタベリー大学　保健科学研究科長代理
Professor Andrew Hornblow,　同研究科　教授

研究指導共同顧問：

米山　万里枝　東京女子医科大学病院　母子センター看護師長

研究主旨をご理解いただき、面接・アンケートのご協力について考えていただければ大変光栄です。質問などございましたら一島のほうへいつでもご連絡、もしくはお声をおかけください。大変、恐縮ですが、この説明書をお手元にお届けした後３－４日以内に面接及びアンケートへのご協力の是否、もしくはご協力について考える時間がもう少し必要であるか等、お伺いさせていただきます。ご検討を頂き、本当にありがとうございます。

ニュージーランド国立カンタベリー大学　大学院修士課程
保健科学研究科　研究生

一島　栄美子
連絡先（携帯）：０８０－６７６３－３８６３
chilli - pop8718@ezweb.ne.jp
（２００７年１１月より２００８年１月末日まで通信可能です）

Health Sciences Centre

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Email: healthsciences@canterbury.ac.nz

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PARENT CONSENT FORM

For participation in the study:

Nursing Roles in Parental Support: A cross-cultural comparison between Neonatal Intensive Care Units in New Zealand and Japan

Please tick to confirm

- o I have read and I understand the attached information sheet dated 13 / 2 / 2008 for volunteers taking part in the study designed to analyse parental stress in Neonatal Intensive Care Units. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

- o I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.

- o I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect continuing medical/ nursing care for my child/ whanau.

- o I understand that all aspects of information in this study including my identity will be kept completely confidential.

- o I have had time to consider whether to take part.

- o I know who to contact if I have any concerns in regard to participating in this study.

- o I consent to the use of my data for future related studies, which have been given approval from a Health & Disability Ethics Committee.

- o I know who to contact if I have any questions about the study.

✳ I wish to receive a brief summary of the study results. Yes / No Please post the summary to: (please write your postal address)_____.

I _____(please print your full name) hereby consent to take part in this study.

Signature (participant):_____Date:_____
Project explained by: Emiko Ichijima **Signature:_____Date:_____**

Contact Details

Researcher:
Emiko (Emi) Ichijima, Registered Nurse, MHealSc student, University of Canterbury
Email: eic14@student.canterbury.ac.nz
Ph: 03 366 7001 ext 8691 (Health Science Centre, University of Canterbury)

Supervisors:
Dr. Ray Kirk, Acting Director, Health Science Centre, University of Canterbury
Prof. Andrew Hornblow, Health Science Centre, University of Canterbury
Ph: 03 366 7001 ext 8691 (Health Science Centre, University of Canterbury)

Dr Nicola Austin, Clinical Director, Neonatal Intensive Care Unit, Christchurch Women's Hospital
Jan McKenzie, Discharge Nurse Facilitator/ Neonatal Outreach Coordinator, Neonatal Intensive Care Unit, Christchurch Women's Hospital

Please do not hesitate to contact Emi or her supervisors at any time if you have any questions or with to discuss your participation.

Appendix K: Parental Consent Form (JP)

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面接およびアンケート協力についての承諾書

研究題目：
両親へのサポートのなかでの看護師の役割： ニュージーランドと日本の新生児集中治療室（NICU）における両親のストレスの要因、及び看護師の役割についての文化的比較考察

下記の各項目についてご確認の上、丸印にチェック（✓）をお願いいたします。

- ‘面接およびアンケートへのご協力のお願い （２００７年１１月)’という上記の研究についての説明書を読み、研究主旨を理解しました。 また、研究内容などについて研究者(一島)と話す機会もあり、この研究への協力についての説明は適当であったと思います。
- この研究への協力(面接・アンケート)について、家族とも話し合う機会がありました。
- この研究への協力は自主的なものであり、面接・アンケートへの協力はいつでも中止できること、また、この協力の中止が子どもと家族への医療・看護に影響を及ぼすことは一切ないと理解しました。
- 面接及びアンケート協力において、私の個人情報が完全に守秘されると理解しました。
- この研究への協力の是非について考える時間がありました。
- この研究について、もしくは研究への協力について、もし何か質問等があった場合、誰に連絡を取ればいいか知っています。

以上により、私 _____(楷書でフルネームをお願いします) は面接およびアンケートへの協力を承諾いたします。

研究協力者(署名)： _____
日付： _____

研究について説明した者(署名)： _____
日付： _____

To all staff in NICU

UNIVERSITY OF CANTERBURY
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Research project: Nursing roles in parental support: a cross-cultural comparison between Neonatal Intensive Care Units (NICU) in New Zealand and Japan

12 March 2008

Nursing support of parents of children born prematurely is vital, over the period of intensive care in NICU and also in the longer term. I will be conducting research on the above topic in the unit between the period of March 2008 and June 2008. The project, which involves a parental interview and questionnaire, has been developed in consultation with Dr Nicola Austin and others, and has appropriate ethical approval. Please refer to the attached parental information sheet for more details.

As the research progresses, I will be in the unit frequently to recruit parents for the study and for interviewing and collecting questionnaires. I would very much appreciate your understanding and support during this process.

The Participants:
Thirty pairs of parents (n = 60) in the NICU in Christchurch Women's Hospital. Parents of consecutive admissions to the unit will be invited to participate in the research until the recruitment target is reached.
The inclusion criteria:

① Biological parents whose child was born prematurely (up to 34 weeks and 6 days gestational age at birth) or has congenital diseases requiring NICU (excluding Nursery) hospitalisation.
② Parents whose child is hospitalised in NICU more than two weeks.
③ Parents with marital or de facto status.
④ Parents who are New Zealand residents for more than 5 years.

The exclusion criteria:

① A child in palliative care
② The child's condition is a result of parental drug abuse.
③ A major parental mental illness

The Method:
1. Parental interview: For general demographic questions
2. Parents complete the questionnaire: *Parent Stress Scale: Neonatal Intensive Care Unit (PPS: NICU)* (Miles, 2002).

Participation in the interviewing process and questionnaire may cause anxiety for some participants. However, it is expected that discussion of issues raised could help reduce the anxiety of the parents. If you have any concerns, please contact me or my supervisors listed below.

Emi Ichijima
Registered Nurse
MHealSc student
University of Canterbury
chilli-pop@xtra.co.nz

Dr Ray Kirk
Health Sciences Centre
University of Canterbury
ray.kirk@canterbury.ac.nz

Prof Andrew Hornblow
Health Sciences Centre
University of Canterbury
andrew.hornblow@canterbury.ac.nz
Or telephone 366 7001 ext. 8691

Dr Nicola Austin
Clinical Director
Neonatal Intensive Care Unit (NICU)
nicola.austin@cdhb.govt.nz

Jan McKenzie
Discharge Facilitator
/Neonatal Outreach Coordinator
NICU
Jan.McKenzie@cdhb.govt.nz

Health Sciences Centre

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Email: healthsciences@canterbury.ac.nz

面接･アンケート実施に当たってのご協力のお願いについて

１１月１２日から来年１月末日の期間、ご両親への３０分程度の面接と無記名アンケートを実施します。　内容に関しては別紙：　面接･アンケートご協力のお願い（ご両親への説明書）をご覧ください。

この間、お忙しいと思いますが、スタッフの皆さんに以下、ご協力をお願い申し上げます。

- 患児およびご両親の状況により、面接・アンケートのお願いをすることが妥当であるかについて事前にご意見をお伺いすることがあります。
- もし、面接・アンケートに関して、ご両親から相談を受けた場合、私のほうへご連絡いただくか、私宛のメモを赤と透明のプラスティックケースににお残しください。連絡先及びメモ用紙はそのケースにあります。
- アンケートは後日持参という形になりますので、もし、私が不在の場合にご両親から渡された場合、黒いケースを残しておきますので、それに入れて頂きますようお願いいたします。

研究対象について：

NICU 入院中の患児の３０組の血縁関係のあるご両親(６０名)

- 患児 - 在胎３４週６日以下で出生、もしくは先天性疾患のために NICU 入院中であること(乳児室・小児科は含まない)
  - 入院後２週間経過していること
- ご両親 - 精神科疾患をもつ、もしくは身体的状態が疾病により著しく不安定な場合、及び家庭内の考慮すべき問題がある場合は対象外となる
  - 日本で生まれ育ち、日本語を母国語とすること

研究に際し、NICU　で働くナースの　１）NICU 平均経験年数、２）平均年齢、３） 性別、について確認させていただきますが、ご了承ください。

皆様のご理解とご協力に感謝いたします。

一島　栄美子
（カンタベリー大学大学院　修士課程　保健科学研究科　研究生）

Parental Comments (New Zealand)

We have been very lucky, to date, that our baby has been very well during our time in NICU and has needed very little intervention. What is really only stressful is the 'unknown' ie. Not having had a prem baby before or actually not being in hospital before – theses are new experiences for us. We have found that the staff working in the NICU have been very reassuring and explain any concerns we might have had which has meant that our experience in this unit has been very good. (Mother)

- Staff very friendly and helpful
- Our baby has been very well so this has led to very low stress, we are lucky.

(Father)

In isolation a lot of the stress I feel able to handle but when they are all combined together they can make me upset and anxious eg: monitors going off, lots of staff and parents, the whole environment, especially if tired.

I found most of the NICU staff fabulous and very supportive it helps to have a very attentive nurse who supports you and helps you eg: gets the chair and pillow, helps get baby out, make sure you are ok and keeps checking to see if you need anything – this attentiveness helps me to feel supported and makes handling the monitors, alarms, tubes and environment etc a lot easier.

It is important to me to have a lot of information about what is going on with my baby and to be as informed as possible. It is helpful when the nurses let you know how baby is doing, how baby's night was etc. It is important that the staff try not to be too loud and chatty as this can add to my stress levels as well.

It becomes more stressful when there are a lot of babies and the staff are stretched as the staff cannot give you the 'one on one' support they could have if it was quieter.

For me, a stressful point has been external – the response from grandparents, not understanding and not being supportive. (Mother)

On the whole communication has been good but occasionally we have been in a situation where information has got to us second hand (eg. "I thought the doctor had discussed this with you" etc.).

Or bad news has been sprung upon us by a consultant/ specialist that must have assumed we had more information than we did at the time. I guess this is just a case of having so many people involved in caring and diagnosis. Another difficulty which is

probably on the whole a result of the above is being offered conflicting advice on how to care for my baby which can be confusing especially when you are in an emotionally vulnerable state.

I would have to say though the support and level of care on the whole has been incredible and greatly appreciated – this helps tremendously in having confidence in caring for our daughter at home. (Mother)

- Before, during and after all surgery (Mother)

Although this has been a very stressful time I have to say I wouldn't have been able to cope without the professionalism and the caring attitude of the NICU staff. They are amazing. (Father)

Having already had a previous pre-term baby in the NICU, I felt I was familiar with the environment and routine and was aware of what to expect rather than it being a foreign/ new experience for me.

Plus my baby did not require ventilation or a lot of tests and interventions but if this was not the case I am sure I would have found the NICU experience very stressful. (Mother)

I find it stressful that procedures are not better explained to me. (Father)

One thing that I do find quite stressful is not being informed, either completely or in layman's terms, about procedures and tests being done as well as changes or additions in medications or supplements. Sometimes I feel I agree to something and only later find out what is actually involved, and if I had that information earlier I might have objected.

I also can find that the attitudes and behaviours of some staff can add to the stress of being in NICU. In particular we have had one nurse who seemed to be telling me that I didn't need to be asking questions and she seemed to get annoyed at me. That behaviour makes me feel that I am not important when it comes to my baby's health. Another time I found that the doctors were suddenly talking in hushed voices where they had been talking normally before. I find it very stressful that there are things that the doctors need to talk about that they think I shouldn't hear. (Mother)

I felt one of the nurses was a bit rough with my baby when he first came to room 4.

(Mother)

Everything about unit helps reduce o/all "stress" o/wise babies wouldn't make it so very grateful for any amount of stress over any grief! (Father)

There are some nights that can be very stressful for myself. At first I would alienate myself from my partner and others that live with us. This however didn't help me get over missing my baby. When I actually let my feelings but to my partner it was then that I was able to relax and feel much better about my baby. I know now that it' s better to talk about my feelings and not bottle them up inside of me. (Mother)

My 7 year old niece has been looking forward to seeing Leigh for ages but hasn't been allowed to see him. (Mother commented on in response to answer the question 9 under parental role: Not being able to share my baby with other family members)

When you give birth to a premature baby, you immediately think the worst. I had no idea that so many premature babies were born and I was really stressed when they took my baby to NICU as I really didn't know anything about this ward or exactly what was happening with my baby i.e. how sick or well he was.
The staff in the NICU ward were brilliant. They explained everything – what the unit does, what was happening to my baby etc. They were also very friendly and I felt I could approach them at any time.
This made the process a lot less stressful as I realised that my baby was in the best place for him, surrounded by people who could help him get bigger and stronger. (Mother)

More stress caused by constant travelling, petrol costs, parking and inability to complete normal household chores, due to being in the hospital. (Father)

Staff were lovely they weren't a problem. Only thing I didn't like is when I'd come in and there was no staff in the nursery at all. Another baby would be crying it's eyes out and I couldn't do anything. This was very unsettling. (Mother)

- Going from level 3, where you have your own space, into level 2 which was exposed to everyone not just a few. This made me feel like I didn't have my own space and the situation was made more daunting knowing that I was going to be there for a

long time because my baby had a number of weeks before going home. One thing to note that we never had a tour of the whole floor so did not know what to expect but I did feel as though there were more private areas within the same area that were not being used and would have been better.

- The amount of staff changes:
  - throughout the day (e.g. 8 hour shifts) and;
  - from day to day and having to get to know different personalities, build up rapport and feeling comfortable questioning new nurses.
- The inconsistency of procedures and ideas amongst nurses e.g.:
  - not being told how many times to try nursing my baby and then a worried nurse saying I should be trying twice a day and it had only been recorded that I had tried once in the last three days, where as I usually try twice a day and just the day before I had tried twice and he had had two really good latching on and sucking episodes that hadn't been recorded.
  - One nurse saying to put him on his back for shaping his head and the next saying to put him on his front for his tummy;
  - Being able to hold him a certain amount of times a day and coming in expecting to be able to hold him and not being able to when his circumstances had not changed (there was not a major reason for this to change e.g. an infection, drop in health etc). (Mother)

- Nurses changing constantly and inconsistency of care between nurses.
- Being unsure if nurses were paying enough attention to my baby. i.e. nurses leaving the room, talking on the phone.
- Not having a clear guide of when certain things should happen. i.e.
  - when to get breast pump
  - when to put clothes on baby

  each nurse seemed to have a different idea about theses things. (Father)

  - Not directing related to NICU, but the cost of carparking was a bit of a stressor. Having a heavy use card now limiting cost to $3 a day helps, but having to pay to part at hospital when you need to be there doesn't seem right. $2.20 per hour is ridiculously expensive.
  - Experience at NICU has been great – thanks. (Father)

I personally found the constant changing of nurses a little frustrating. (Mother)

I found that all the nurses have slightly different rules we have to follow and this gets stressful as I'm afraid of being 'told off' for doing the wrong thing. All the nurses are great though and just have different opinions. (Mother)

The evacuation procedure for an actual Fire Alarm needed a bit of work.
① leadership in acr room to get baby ready to go.
② Knowing where to evacuate too.
There was an actual Alarm to Evacuate the Floor. (Father)

Not being able to hold him when he was first born. (Mother)

Even though it was hard having/ leaving my baby in NICU it was good to know he was well looked after. Thanks to NICU. (Mother)

Outstanding staff support for parents and calm environment in NICU. (Father)

The staff in NICU have been increadibl! However, due to high staff turnover and the huge amount of information to be communicated to new parents, there are expected lapses of communication. Eg: same information from several different sources (Good!) or some information NOT being discussed. We experienced this with the "visitor" list and had an expectation this extended to the touching of the child while still in the incubator. This caused some distress for the grandparents when 3 weeks later, they were asked to remove their hands from the incubator. I'm sure this could have been resolved sooner if we as parents had known the questions to ask, but as the saying goes: - you don't know what you don't know??

Becoming more confident as a parents & mother, I am now able to ask questions more readily and have relaxed into being a NICU parent. That said we have been very lucky as our child is happy, healthy and strong. We are able to spend time at home knowing that our child is well , for the moment, is in the best place possible. Thank you. (Mother)

The kindness of the nurse's has helped a lot in my understanding of what is being done to my child and therefore it has helped my stress level. Also, the ability to touch and hold my child from day 1 has been very important to my partner and myself. The support from my family is an immense help to my partner and I. Knowing that the nurse's are caring for her so passionately is a great relief when I am not @ the hospital.

(Father)

The fact that depending on which staff member was caring for our babies would depend on how much information that would give you and how much they would encourage you to help care for your baby. We didn't get any information from the doctors only from the nurses/ midwives and then it was quite often only after you asked them questions.

Also the fact that after having a caesarean section the mother is discharged, not being to able to drive and yet is expected to keep up the milk supply for their babies and be there for feed times. (Mother)

The single biggest stress factor for me is the lack of information about progress. Everything I learned I had to get from the information pack given to us on day one. The trouble is when you are working, driving 2 hours a day, and trying to get sleep, you don't have a lot of time to read a pile of information.

The doctor looking after our children hasn't spoken to us at all, and we rely on nursing staff for that information and some nurses are better at supplying it than others. So we often are left wondering what is happening and what is next, when can we go home etc…

I am finding it better now because I ask more questions but early on I was busy looking after my kids and my wife and needed people to tell me what was happening. (Father)

- Main Stressful situation for me was when he was hooked up to monitors & them going off(alarming) & feeling awkard moving/ holding him his size and all the wires etc. Also seeing the IV in his hand.
- The size of him and helplessness I felt in first few days was very very stressful & upsetting seeing him struggling & in pain without having control over helping him.
- All the wonderful nurses in Room 2 have been wonderful & really helped us become more confident which has made the experience less stressful. They are not pushy & very understanding & know when to step in & help. (Mother)

Thank god there are places like NICU! (Father)

- Being unsure of my role as a mother in NICU
- Not sure of expectation of hours of being with my child in NICU
- I find it very stressful being away from my child
- It is very difficult to get to the hospital and home again as I can't drive. This has

caused a lot of stress for me. (Mother)

Differing understanding of nurses as to the level of involvement I want to have in baby's care. Ie; some nurses good at encouraging me to try new things with him like lying him out of incubator myself, helps me to gain confidence and feel 'competent'. Other nurses although not meaning to would perhaps assume that I knew how to do everything and I began to feel stupid to ask for help with some things. I think it was perhaps their way of encouraging parental involvement but at times it has made my already low confidence a bit lower as well as leaving me feeling frustrated. Certainly not a complaint as all the care is amazing, just as observation that I have found it a bit hard at times in regard. (Mother)

Parental Comments (Japan)

Continuing expressing breast milk even though separated from my child. I know this is the only thing I can do while I am not with my child, but I am still worried about the amount I am producing, or I feel guilty when I am not able to get up to express during the night. I feel isolated. (Mother)

Not being able to know about test results instantly. Staff seem to be very busy. (Mother)

Only being able to use a digital camera within a certain time. This limits the chance to take a good shot of my baby and it is stressful. Although we are allowed to use a disposable camera, the quality of these photos is not good enough, so it has been stressful every time I have got the photos developed. I wonder if I can take pictures whenever I want with my digital camera.

I would like to have a specific explanation/ information regarding possible processes for babies who are born at a similar gestation to my baby, like physical growth at a particular age, or a time-line for weaning off from a respirator, general milestones, and possible issues that might arise for the family as well as their probability. (Father)

I think it is not understandable that no one is able to talk about my child's test results only because my child's team doctors are not present in the unit. The other doctors should tell the parents the results if they are available. This would help relieve us, the parents, from anxiety.

I sometimes wonder if the nurses communicate well enough to carry on nursing care. I agree that it is impossible for all nurses to provide identical care. But, I think showing too much inconsistency is not acceptable. Eg. Tube feeding(by machine) was set to take one hour then suddenly changed to 20 minutes, then back to an hour the next day. (Father)

The time limitation for visiting hours and taking pictures with the digital camera.

Visiting hours: If they were a bit longer, then my husband could see our baby much longer.

Taking pictures with the digital camera: it is only a resource to have my baby's lovely image with me while being separated from my baby, so I would like to have it at all times. But, the time limitation for taking pictures (with digital camera) means that we can miss the perfect shot. It is not possible to take beautiful photos with the instant camera as the lighting in NICU is too dark.

At admission, I would have liked to have had a booklet of any kind about possible future medical/ surgical treatment and development so that I could have known what was going to happen.

Getting worried about things from varied sources of information as there are limitations to search for unknown things. Being confused by medical jargon and I feel that the doctors are always telling me about treatment suddenly.

I would like to know about past studies of NICU babies.

It would be helpful to know about someone else's experience of seeing an extremely small baby eventually graduate as a healthy infant from NICU. (Mother)

I was thinking about the reasons why my baby was born prematurely, necessitating being in an incubator, and if I did wrong. (Mother)

I feel afraid of talking to my baby in case I am too loud. (Mother)

I miss my babies very much as I am not able to see them everyday because I live far away from hospital.

I gave birth to my babies after a renal transplant and I am feeling unwell. I feel tense thinking I have to get better before their discharge. Also, I am worried about how I would cope with child rearing if I end up going back to dialysis.

I wonder if I could stay at the hospital for a couple nights before they are discharged home to learn about caring for my babies, as I cannot come to the hospital everyday like other mothers. I am anxious about managing 24 hours 7days right after their discharge.Anyway, I am just wondering, as I hear some other hospitals offer the option. (Mother)

I get stressed when discussing operations for my baby. I still feel unsure afterwards.

It is stressful seeing my baby being transferred to the theatre, the waiting area and the time while waiting. (Mother)

Pre operative discussion, such as about process of operations.

Seeing my baby being transferred to the theatre.

Waiting time. (Father)

As it is my first time to have a child, I cannot compare the situation from my experience and so I feel OK to accept the situation as it is. So I did not feel stressed

much. (Father)

When [my baby was] being admitted to the unit, I was anxious about seeing my baby in an incubator, thinking when can my baby come out. My baby was born at 34 weeks gestational age and was small, I was worried every day wondering if my baby would grow well. As my baby is gaining weight and feeding well, I have become less worried.

The most stressful thing is that I am not able to be with my son all the time, but I do not feel too stressed as my son's primary nurse and other staff are looking after my son tendaerly. I am thankful for being able to learn from experiences in the NICU as a parent. (Mother)

I wonder if the visiting hours could be a bit longer. (Father)

I gave birth to my twin babies at 26 weeks gestational age. I lost one of the girls, and the other one is in the NICU, but I was thankful for the nurse who gave my child a nickname. Since then, I call her by her nickname whenever talking to her. I felt very relieved at that time with having the nickname for my baby.

It is difficult for me having the same expressing room as the mothers who have a healthy baby.

Although in the questionnaire there is a question about having a respirator for my baby, I feel relieved to see my baby getting the appropriate treatment. It is heaps better than getting prolonged damage to my baby's brain due to lack of oxygen.

I feel relieved to see many staff working in the NICU. It was my choice to admit to this hospital for this reason, so thank you. (Mother)

When nurses are busy or under staffed I feel afraid to ask about my baby. I wonder if nurses could pay more attention to the parents during visiting hours as it would help us feel more comfortable to ask questions. My husband in particular finds that no one talks to him and so he goes off after a brief visit as he feels uneasy staying in the unit longer, so it has been stressful for him. Also, when it is impossible to get doctors when we would like to see them, or to answer our questions, it would be helpful to have answers at the next visit. I understand it is our responsibility to ask all the questions, but I feel uneasy doing so. (Mother)

Thank you very much for looking after my baby 24 hours 7days. I feel worried about having my baby in the NICU, but, on the other hand, I have been thankful for the situation as I was not ready at all when I had an emergency preterm delivery, and this

caused the other stresses that I have had to cope with physically and emotionally.

However, there has been one occasion on which I felt very upset (and as a consequence) did not want a particular nurse to look after my child. When I visited my baby, I saw that the nurse who was looking after my child seemed to be quite rough to my baby, who was quite lethargic, not even crying, and vomiting at the end. I struggled with whether or not to tell the charge nurse about my feeling about the nurse, but as the other nurses were so great to my baby, I decided not to, but I cried. I could not help myself crying in the situation with the stress and anxiety I felt.

I am only able to see my baby every second day for two hours as I live far away, so I feel sorry for leaving my baby alone. (Mother)

Staying at the NICU hasn't caused me much stress as I think it is good for my baby. Rather, telling my relatives or friends about my newborn baby has caused me stress. Although they are delighted to ask for my baby's photo, I cannot show it to them as I only have a photo of my baby with medical equipment, or photos of bad quality due to the instant camera. Friends gave me clothes for my baby, but they don't fit as they are too big. Also, I cannot answer questions about when my baby's going to be discharged, etc. I know they don't mean to upset me, but I feel stressed and I cannot be delighted. "Can we really go home?" "Is my baby going to deteriorate?" "Is my baby going to grow?" I was too anxious to be thankful to others.

I lost confidence and was hurt by the nurse's comment, 'I will feed your baby next time', as I felt 'I am not doing the right thing for my baby.' Also, I feel upset to see nurses' attitudes when they are feeding babies. They feed babies as if they have to do so because of their 'job'. Although I understand feeding a baby is one of the routine nursing cares, it is obvious from their attitude that they are feeding babies just because it is their 'job'. It would be OK to do their 'job' in the way they do when parents are not around, but when we are here, it would be better to see nurses 'loving the babies', so we would feel relieved and less anxious, thinking my baby is well looked after and loved while we are not in the unit.

On the other hand, it was a pleasure to see nurses making special pretty tapes for the NG tube, cutting out animal shapes, etc. It makes a warmer atmosphere in the NICU amongst all the medical equipment. (Mother)

My situation was that my child was admitted to the NICU and my wife was in MFICU. I was struggling and looking for things that I could do. A couple of days later, I came up with the conclusion that the only thing I could do was to work as usual, and leaving the

two at the hospital was a good thing for them. What has been causing stress has been the people around us rather than being in the hospital. I have felt stressed when being asked about my child and wife so I have avoided talking about it with others. (Father)

I think parents would feel sorry for their baby, seeing all sorts of medical equipment applied to them due to the child's complex medical condition. It is better by far for parents to see their child born healthy with no medical problems. Our child was born prematurely by emergency C-section at 34 weeks and 3 days, weighing 1914g. She has been a month in the unit - she is growing well, showing no evidence of developing medical problems, now weighing 2760g and we are soon to be going home. This positive progress is due to the nursing care for our baby 24 hours a day 7 days a week. I believe the nurses' devoted effort is not only a work obligation and we feel relieved that our baby is in good hands. I would like to thank them from the bottom of my heart. I have never felt stressed by the nursing staff. (Father)

‘お子さんが NICU に入院している間で、何かストレスに感じたこと、またはご意見があればこちらにご記入ください’という質問に対するご両親からのコメント

子どもと離れているのに搾乳を続けること。　はなれていて出来るのはこれくらいしかないと思っても出る量が心配で一喜一憂したり、夜中に起きられずに自分を責めたり、なかなか孤独な作業です。　(母)

検査の結果をすぐに聞くことが出来ない。　スタッフがとても忙しそう。　(母)

写真(デジカメ)を撮影しないのに、決められた時間しかできない。これはよい表情の写真が取れず、ストレスを感じた。使い捨てカメラの撮影は OK であるが、やはり現像するとピンボケなどが多く現像するとピンボケなどが多く、現像のたびにストレスを感じ、好きなときにデジカメで撮影できたらいいのに、と思った。

自分の子どもの大きさの場合、いつ頃どれくらいの大きさになるか、いつ頃人工呼吸器がはずれるとか、一般的な成長速度やその家庭で発生する可能性がある問題やその確立などを事前に教えて欲しい。(父)

子どもの検査結果を担当医が不在なので教えられないというのは不思議。　結果がでているなら、説明できる人がすればよいと思う。　親としてはなるべく不安をとり除きたいので。

看護師さん同士で情報が伝わっていないのかな？　と思うことがある。　看護方法が全員同じは不可能だと思うが、「えっ昨日とやっていることが違うよ」という位に方法が違うのは変。(胃カテによる母乳注入時間が１時間かけていたのが急に２０分になり次の日は１時間だったりとか)　(父)

- 面会時間、デジカメ撮影時間が制限されていること。
- 面会時間：　平日の夜もう少し遅くまで面会できれば、夫がより長く子どもに会える。
- デジカメ撮影時間：　会えない時間の頼りは子どもがかわいく写っている写真しかなく、携帯の待ちうけなどにして常に持ち歩きたいが、撮影時間が制限されていると撮りたい瞬間が撮れない。　使い捨てカメラは NICU 内の明るさではキレイに撮れない。
- 入院してすぐ、今後の治療や成長についての大よその目安となる資料が欲しい。
- 入院後３ヶ月経って、森永乳業の「私の面会日記」が置かれていた（洗面所）が、ネットや本で調べるには限界があり、余計な情報を目にして不安になる事もある。　専門用語にとどまったり、いつも突然医師から治療について説明があった印象がある。
- 先行事例がほしい。
- 超低出生体重児でもこんなに元気になっています、という具体的な体験レポートのよ

うなものがあれば、安心になるため。　（母）

自分の何が悪くて早く小さく生まれてしまい保育器に入らなければいけなくなってしまったのかとても考えてしまった。　(母)

子どもに声をかける事が気になる。　周囲にうるさいか気がかり。　(母)

子どもが出産して、内臓や体質に異常があった場合には、様々な器具が取り付けられて子供が痛々しく感じられることが、その立場になった親は感じると思う。　五体満足に生まれて、さらに体に何も異常がなければ親は一番よいことと感じられるでしょう。　今回、私たちの子供は１９１４ｇの未熟児で３４週３日目に帝王切開の手術をして無事出産し、ちょうど１ヶ月で退院することとなりましたが、内臓や体質に重大な後遺症が残る異常な症状もなく順調に育って２７６０ｇ余りに成長しました。それも一重に NICU のスタッフの皆様の２４時間体制で子供を見守り看護してくれたおかげです。　私は、そういう彼女達の仕事上専門的に行う義務があると思いますが、献身的な努力のうえに子供が育ってくれたという安心のうえにも信頼性があり感謝の気持ちで一杯です。NICU　のスタッフの皆さんに関して特にストレスを感じたことはありませんでした。　(父)

- 家が遠いので毎日会えない事が淋しい。
- 腎移植後の出産、今あまり体調がよくない。　退院までに早く治さないといけない気持ちであせってしまう。　又、透析になったら育児をどうしようと考えてしまう。
- 子ども達が退院のとき、その前に２泊３日で病院に泊まっていろいろ勉強したい。　通常の人は退院まで一緒にいていろいろ勉強できるので・・・　いきなり退院して２４時間一緒にいて、出来るか心配。　他の病院では出来る所もあるらしいので・・・　でもムリですネ。　(母)

- 子供の手術のスケジュールの打ち合わせにストレスを感じます。　不安がのこります。
- 手術室までの搬送される様や手術中の待機場所や時間についてストレスを感じます。(母)

- 子供の手術スケジュール等のうち合わせ(術式内容等)
- 手術室へ搬送されていく様を見たとき
- 術中の待機時間　　（父）

初めての子供なので、経験による比較ができず、普通に状況をうけいれたれたため、それほどストレスは感じませんでした。　(父)

はじめは、保育器に入っていた為、いつまで入っているのだろうか？という不安がありました。　週数も３４週で産まれ、体重も少なかった為、健康に育ってくれるか、毎日不安な気持ちはありました。　除々に体重も増え、おっぱいも飲める様になるにつれて、すこしずつ不安は解消されて来ました。

息子のそばにいつもいてあげられない事が一番のストレスですが、受け持ちの看護師さんやその日その日の担当の方が、息子に愛を持って接してくださっているので、強い不安は感じていません。NICU に入院している事で、親としてとてもいい経験をさせてもらっていると思っています。（母）

面会時間があと少し長くあったらもっと助かったと思いました。（父）

- 私の出産は２６Ｗ０Ｄの MM 双胎であった。１児死亡、１児 NICU　という結果となったが、亡くなった子（未知香）のことを主任さんが‘みっちゃん’とニックネームをつけて呼んでくれたことが、とてもありがたかった。　私もそれ以来、子供にみっちゃんと話しかけている。　主任さんの「みっちゃん」にとても救われた。　ありがとうございました。
- 搾乳スペースが健康な赤ちゃんのお母さんと一緒なのが少し辛い。
- アンケートで呼吸器等医療機器についての質問があったが、私は、娘が適切な医療処置をうけられる様子を見て、かえって安心する。　酸素不足で脳に障害でるよりナンボもましです。
- NICU　に行くと大勢のスタッフさんがいて安心する。私の場合は何かあったとき、女子医大の NICU に子供を入れたくてここで出産した。　退院まで、まだ山あり谷ありだと思いますが、今後ともよろしくお願いします。（母）

面会に行った時、バタバタしている時や看護婦さん等が少なく手があいていない時、子供の状況を聞きたくてもこちらからなかなか声をかけずらくそんな時に少しでも声を看護婦さんから、かけてもらえると、色々と聞きやすく安心するのでそのへんのかいぜんをしてほしいと思います。　特に主人は、誰からも声をかけてもらえず、面会に行きたくてもすごくいずらいためか、子供の顔をみてすぐに帰ってきてしまうため、かなりストレスを感じているようです。　又、先生と話しをしたい時、質問のある場合、その時、わからなければ次の面会の時、その答えを教えてくれたらなおいいです。　子供のことなので自分から色々聞かなくてはいけないのですが、なかなか自分から聞けないため、その点をよろしくお願いします。（母）

スタッフの皆様には２４時間体制で小さな我が子の面倒をみて頂き大変感謝しております。　アンケートにお答えした様に、やはり我が子が予定より早く小さく産まれ NICU に

入院しなくてはならない事には色々と不安がありますが、反面私自身緊急入院で心も体も何の準備もないままあっという間の色々な出来事にまた違ったストレスをかかえる身にはとてもありがたく安心を頂いてもおります。

ただある日、自分は退院し子供のところへ行った時、ある担当のスタッフの方（２月１３日昼担当の方）の子供に対する対応が乱暴に見え、子供も泣きもせず元気がなく、ミルクも吐いたりした時には“この方にはもう我が子をみてほしくない”と思ってしまいました・・・。　平原主任さんにそのことをお伝えしようかとも思いましたが他のスタッフの皆様がよくしてくださっている中、わがままを申し上げるのもどうかと悩みましたが、思わずストレスと不安でその場で泣いてしまいました・・・。

また病院と自宅（千葉・柏）が少し遠いため、１日おき２時間くらいしか会えず、子供にもさびしい思いをさせて申し訳ない、という気持ちです。（母）

NICU に入院している事自体は子供の為と考えると仕方のない事と割り切る事ができるのでそれほどストレスを感じなかった。むしろ、出産した、ということを親族、友人に祝ってもらうことにストレスを感じた。　「写真を見せて」と言われても、医療器具に囲まれた写真、使い捨てカメラのピントのぼけた写真しかない、「赤ちゃんに」ともらった服もサイズが合わない、「退院はいつ？」と聞かれても明確には答えられない、等々。　悪意なく、純粋に祝ってくれる周囲の気持ちが逆にストレスになり、素直に喜べなかった。　「本当に退院できる？」「悪化しないか？」「ちゃんと成長できるのか？」といった不安で一杯なので周囲の好意にこたえられなかった。

ミルクの飲みが良くない時に、看護師さんの「次は私があげます」の何気ない一言に「自分のやり方が悪いのか」と自信をなくし、傷ついた事もあった。　又、看護師さん達にとっては医療行為であり、日常の作業なのかもしれないが、ミルクを与える事を『作業』という感じ丸出しでされるとすごく辛い気持ちになった。　母親の見ていない所では、それでも良いかもしれないが、せめて母親が見ている間くらいは「あぁ母親がいなくてもかわいがってもらってる」と安心させてもらえるような態度で接して欲しいと感じた。

逆に鼻に入っているチューブをとめるテープを看護師さん達が可愛い動物の模様を書いて貼ってくれているのにはすごく癒された。冷たい感じのする医療器械の中で、暖かい感じがして大変嬉しかった。　（母）

子供が、NICU、妻が MFICU　には入るという状況でした。　自分が出来ることを探し、悩みましたが、２，３日かけて、今やれることは日常通り働くことしかないと割り切り、その後は病院に居ることが一番二人にとってもわたしにとっても良い状況であると考えていました。　ストレスは病院よりも周囲の人間関係でした。　悪意は皆ないのですが、「どうなった」と聞かれることが、ストレスに感じると思ったので、極力、子供の話はしないようにしていました。　（父）